

Sacramento RAC Regional Advisory Committee Agenda



| Date | Tuesday, February 12, 2019 | |
|----------|--|--|
| Time | 10:00 a.m 1:00 p.m. | |
| Location | Note new location: 3841 North Freeway Blvd. Suite 165, Sacramento, CA | |
| | 95834. (Different building in our same complex) If lost call 916-715-7057. | |

Pursuant to Government code Sections 11123.1 and 11125(f), individuals with disabilities who require accessible alternative formats of the agenda and related meeting materials and/or auxiliary aids/services to participate in this meeting should contact Kathy Brian at (916) 263-8133 or by email to: kathy.brian@scdd.ca.gov. Requests must be received by 5:00 p.m., February 5, 2019.

- 1) Call to Order, Chairperson, Karen Mulvany (FA)
 - 10:00 a.m.
 - a. Welcome RAC Members & Introductions
- 2) Approval of RAC Agenda, Karen Mulvany (FA) (action)
- 3) Approval of RAC Minutes, 10/23/18 & 12/11/18, Karen Mulvany (FA) (action)
- 4) Brief reports from RAC members on issues in their counties (2-3 min.)
- 5) Public Comment Period
 - This item is for members of the public only to provide comments and/or present information to the RAC on matters not on the agenda. Each person will be afforded up to three minutes to speak. Written requests, if any, will be considered first.
- 6) Alta California Regional Center update on services, Jason Lindo, ACRC
- 7) Statewide Self-Advocacy Network (SSAN) Report, Lisa Cooley (SA)
- 8) Sacramento Region, Statewide Performance Highlights (17/18), Policy Priorities (19/20), Grant 39 Review, Grant 41 Summary, Sonya Bingaman (staff)
- 9) Approve 2019 Meeting Schedule and Agenda items for next meeting (4/16/19), Karen Mulvany (FA) (action)
- 10) Presentation by Jordan Lindsey, Executive Director, The ARC California
- 11) Breakout discussions on 1) Dental Services and 2) Abuse/neglect in day programs and the community. (Please read 2 articles in this packet prior to meeting, if possible.)
- 12) Adjournment Karen Mulvany (FA)

Special Note: This is a public meeting, everyone is welcome to attend. Your input, comments, concerns, suggestions, are all welcome! We look forward to meeting you!

Google Maps Page 1 of 1

Google Maps





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N. Freeway Blvd.

north-east of our building. You can drive around to building sayl and then wall toward middle of building, Suite 165. Weil We will have the RAC in a building post signs.



Regional Advisory Committee Minutes Unapproved

| Date | Tuesday, October 23, 2018 | |
|----------|---------------------------|--|
| Time | 10:00 a.m 1:00 p.m. | |
| Location | SCDD Office | |

| Members Present | Members Absent | Others Attending |
|-----------------------|----------------------------------|--|
| Karen Mulvany (FA) | Donnell Kenworthy (FA) (excused) | Aimee Rouiz |
| Jesana Tran (FA) | Colleen Moss (FA) | Nicole Mion, Help Me Grow Yolo |
| Brandy Boyd (FA) | Tyler Busselen (SA) | Meghan Murphy, Help Me Grow Sacramento |
| Elaine Linn (FA) | Christine Hickey (FA) | Kimberly Meade |
| Tony Biondi (SA) | Nancy Esparza (SA) | Kenya Martinez |
| Jane Taylor (FA) | | Benita Ayala |
| Tyson Whitman (SA) | | |
| Glenda Servantes (FA) | | Kathy Brian, SCDD Staff |
| Joyce McNair (FA) | | Vicki Smith, SCDD Staff |

1) Call to Order, Chairperson, Karen Mulvany (FA)

10:14 a.m.

Welcome RAC Members & Introductions

2) Approval of RAC Agenda, Karen Mulvany (FA)

(action)

1st Jesana Tran

2nd Brandy Boyd

Unanimous approval

3) Approval of RAC Minutes from July 17, 2018, Karen Mulvany (FA) (action)
Karen Mulvany amendment comment – section about portrait of services/goal 3 housing/2nd to last bullet: change autistics to people with autism

1st Brandy Boyd 2nd Joyce McNair

Unanimous approval

4) Brief reports from RAC members on issues in their counties

Glenda Servantes (Yuba)

 Talking to business people to create employment opportunities for people with special needs. Most things outsourced to Yuba City but outlying rural areas have needs that are not being met. Transportation is an issue. Need more in Yuba County, closer to where people live.

Brandy Boyd (At-Large)

- 22q meeting @ UCDavis MIND Institute on Sun 10/21/2018
- 22q at the Zoo awareness event will be 5/19/2019
- Warmline hosting transition resource fair on 11/28/2018
- Santa Day at Alta is on 12/14/2018
- Warmline Sac Adventure playground 1st Sat in Nov (11/3-4/2018; last grant weekend) open 2 hours ahead of public for children with disabilities. Ages 7-17
- Libraries in Sac are expanding special needs programming, Library Insiders older youth/young adults; special needs programming page on their website http://www.saclibrary.org/Services/Autism-and-special-needs-services
- Adaptive dance program for adults in Roseville
- Going thru transition process w/17.5-year-old. Navigating transition/employment very challenging even for very knowledgeable parent. Little coordination of services.
 - Would like to have Dept. of Rehabilitation present on their programs, including the Student Services program. Have intake but no programs. May not be ready to roll out/implement fully
 - Transition Partnership Program School Districts
- Comment from public: Parent signed up son for Vocational Rehabilitation when 14.
- State Council's sponsored SB 1274 bill passed on Employment First coordination lifting restrictions on info sharing between DDS and DSS (CalWorks and CalFresh).

Joyce McNair (Sacramento)

- Self-determination comments:
 - o Person centered planning is the core of self determination
 - Decisions made at the meeting will go into IPP
- Next self-determination advisory committee meeting at Alta Regional Center 11/14/2018, 10am-12pm.
- Regional centers need to know how to do Person Centered Planning 2020.
- FREED has a program set up for person centered planning a worksheet

Jane Taylor (Nevada)

 Nevada Co. and Grass Valley – she's having trouble getting services; disagreement with ACRC about day program services for her son.

Jesana Tran (Alpine, Colusa, Sierra)

- Provided information on Family Soup programs http://www.familysoup.org/
- Programs in pre-schools in Yuba and Sutter Counties

- Cinemark collaboration for movie showings Nov (the Grinch); Jan (Mary Poppins)
- Disability Rights CA (Brittany Gillespie) workshop on IEP vs. 504
 - O DRC indicates it can't represent son at IEP until he gives consent, even though she has conservatorship
 - Challenges became bigger when son moved past 18
 - Brandy suggested contacting Warmline for assistance

Elaine Linn (At-Large)

- Young Life may provide social opportunities for youth and adults with disabilities –
 general Young Life high school groups & Capernaum special needs ministry
- Folsom Cordova school board candidate is familiar with disabilities and currently serves on the Community Advisory Committee.

Karen Mulvany (El Dorado, Chairperson)

- 7/19/2018 attended statewide self-determination meeting
- 7/24/2018 ABC 10 interview on accessory dwelling units in El Dorado County: https://www.abc10.com/article/news/local/california/california-bill-would-ease-restrictions-on-granny-flats/103-577133326
- 8/23/2018 Special Moms for Special Kids parent group EDH
 - Presentation from Able Kids Applied Behavior Analysis (ABA): Highly recommended by parents with children with autism. Was vendored as Just4J in the Bay Area but not vendored by ACRC; contracts with insurance companies. http://www.ablekidsco.com/
- 8/24/2018 ACRC Community Resource Development Plan Meeting Community
 placement plan (CPP) dollars are being freed up as prior residents of Developmental
 Centers complete their transition to community living, creating funding opportunities to
 serve other consumers community input requested on how to use dollars
 - ACRC placing initial emphasis on crisis homes and transportation to health care for people in day programs
- 8/30: DDS HCBS Advisory Group meeting: first since February
 - Department of Developmental Services shifting focus back to HCBS waiver, having just completed Self Determination waiver which establishes some precedent for HCBS.
- 10/4-5/2018 Lanterman Housing Alliance (LHA) Summit meeting.
 Strategic Framework initial draft can be seen at <a href="https://scdd.ca.gov/wp-content/uploads/sites/33/2018/09/STATEWIDE-STRATEGIC-FRAMEWORK-FOR-EXPANDING-HOUSING-OPPORTUNITIES-FOR-PEOPLE-WITH-INTELLECTUAL-AND-DEVELOPMENTAL-DISABILITIES-09.18.18.pdf;

but SCDD is amending the document before it sends it out for public comment and final review.

 LHA focus is primarily government subsidized housing; family funded housing including ADUs is beginning to receive more attention

- Input from regional center participant: some Regional Center catchment areas do not receive subsidies for affordable housing projects as they are too rural to meet density and transportation hub requirements, but they are better positioned to pursue ADU housing options.
- Assembly member Jim Frazier He has asked Lanterman Housing Alliance to give him for an IDD housing bill to sponsor
- 8/13/2018 and 10/22/2018 Legislative Public Policy Committee (SCDD committee) meetings:
 - In addition to SB 1274, AB 2657 seclusion and restraint bill sponsored by DRC passed to restrict this in schools
 - Work on strategic planning
 - Opportunity for electronic marketplace of service providers with consumer reviews to support Self Determination rollout
 - Potential work may be needed to retain in California current rights to community integrated work, activities and living.
 - Thanks to ACRC, request for emergency vendorization for supportive living services after provider recently resigned was approved and enabled a successful transition to a new provider (Karen provided information to a parent who questioned what Supportive Living Services is – when an adult child is not living at parent's home; supports independent living)
- CalABLE may be available in December
 - Federal program individual with disabilities may save and invest up to \$100,000 and use funds for Qualified Disability Expenses without affecting services/benefits (SSI, Medi-Cal)
 - o Karen recently opened a ABLE account for her adult child in Ohio
 - When CalABLE is up and running, an out of state ABLE account can be rolled over to a CalABLE account.
- Fair hearing request with Social Security Administration was filed in March 2018, but SSA office has refused to file with court, even with representation from Legal Services of Northern CA. Requesting input from advocates on similar experiences? May be El Dorado County issue.
 - O Joyce McNair input: Beneficiaries can use SSA office in other areas don't need to stay in your own county
- El Dorado County Office of Education has created volunteer job shadow program for special needs students (Wanalynn Alexander)
 - Hoping to develop a template to share
- Note to parents with adult children transitioning out of California Children's Services:
 - O You will receive only a few weeks advance notice of a mandated change from fee for service MediCal to managed care MediCal:
 - Your child's doctors may need to be changed; some temporary extension of existing providers is possible.
 - Be prepared for a disruption in insurance and a temporary loss of coverage.
- Attending El Dorado County planning meeting with Kathy Brian to discuss IDD housing

- 5) Public Comment Period
 - Kenya Martinez
 Coalition for students with disabilities developed because Sac City USD has racial disparities. Partnering with The Arc of CA for advocacy related to racial disparities making sure regional center funding is distributed equally
 - Angel Picon is ARC director of activities
 - Suggested by RAC member: would like to have parent whose child was chosen for self-determination to discuss their experience
- 6) Alta California Regional Center update on services (ACRC staff)
 Not in attendance.
 - RAC members noted there has not been an Alta representative to give a report for the last 2 meetings. Kathy Brian reported that Alta is not mandated to attend and typically were coming to the RAC but due to scheduling conflicts were unable to attend.
 - RAC member suggested to reach out to Phil Bonnet, Executive Director of Alta.
 - Karen Mulvany & Kathy Brian to connect to reach out to Phil & Jason Lindo
 - Kathy Brian suggested that RAC members attend Alta board meetings as they are a good opportunity to receive information and share public comments.
- 7) Statewide Self-Advocacy Network (SSAN) Report, Lisa Cooley (SA) Not in attendance (Lisa attempted but phone line did not open)
- 8) Sacramento Regional Office August/September/October Highlights, Kathy Brian

Activities for JULY - OCTOBER 2018

- 1.1 The Council will increase knowledge about self-determination and person-centered planning by monitoring, supporting and actively engaging in the implementation of the Self-Determination Program.
 - Distributed Self-Determination information at the El Dorado, Sacramento, Nevada,
 Placer, Yuba and Sutter County (SELPA) meetings
 - Attended the Self-Determination Advisory Committee at Alta California Regional Center.
 - Provided and information table at the UCD MIND Institute Summer Seminar
 - Participated in the local Self-Determination Advisory Committee at Alta California Regional Center.
 - Met with Alta California Regional Center to plan for Self-Determination Program trainings this Spring.

- Staff co-lead (with FREED) a session on Person Centered Planning at the Aging and Disability Conference in Nevada County.
- Staff participated in the local Self-Determination Advisory Committee (ACRC)'s meeting.
 Implementation and the role of the local SDAC was discussed.
- Attended the Self-Determination (SDP) Workgroup meeting at the Department of Developmental Services.
- Staff co-presented on Self-Determination with Alta California Regional Center Service Coordinators about the Self-Determination Program to 22 Spanish speaking parent advocates at UCD Mind Institute.
- Attended and participated in the Person-Centered Planning (PCP) Training in Tehama County.
- Staff provided a training on Person Centered Planning to 10 staff (which included 2 selfadvocates) at Easter Seals Day Program in Citrus Heights.

2.1 The Council will increase and promote culturally competent strategies and resources that facilitate competitive, integrated employment (CIE) of people with I/DD.

- Attended the Consumer Advisory Committee (CAC) at ACRC.
- Met with One Stop Job Center of Sacramento and Yolo Counties for providing as easy access to information on employment opportunities and the employment center services available for people with I/DD.
- Attended and provided information at the Colusa, El Dorado, Sacramento, Nevada, Yuba and Sutter County SELPA CAC meetings
- Attended the Business Advisory Council (BAC) monthly planning meetings and planned for an Employer recognition event.
- Attended the Colusa, Yuba, Sutter, Yolo counties Align meeting and provided information about DOR, DDS and CDE's efforts for CIE and the blueprint plans for people with ID/DD and for collaborating with local workforce agencies and community members/leaders to promote the inclusion of CIE for people with I/DD.
- Staff provided outreach information on the SCDD at the Rural Regional Alliance (RRA)
 Team meeting in Woodland
- Hosted the filming of consumers telling their story of employment and College, by Cindy Ruder.
- Met with the Student Services staff at Woodland Community College and provided information about SCDD.
- SACRO staff provided outreach information on the CalABLE, The Business Advisory Council, and Student Services support service at the Department of Rehabilitation at all community meetings.
- Attended and participated in the Supported Life Conference Planning meeting.

- Attended the Yolo County Workforce Innovation Board meeting.
- Attended the WIOA information meeting of the DOR at the West Sacramento library for gaining information on the WIOA implementation for people ages 16-24 years.
- Staff provided written materials on competitive, integrated employment at the 3rd annual Disability Fair at the California State Capital.

3.1 The Council will work with housing entities to increase the development and/or provision of community housing for people with I/DD.

- Staff provided an information table at the Aging and Disability Conference in Grass Valley.
- Distributed information about CalABLE at the SELPA CAC meetings and the Supported Life Conference.
- Attended the Residential Vendor Forum at Alta California Regional Center (ACRC)
- Staff and RAC member will meet again with 2 County Planners for El Dorado County to discuss various possibilities to increase housing options for people with IDD.
- Attended and participated in planning meeting for the Sacramento Housing Alliance's Housing Conference scheduled for October 2018.

3.2 The Council will identify and decrease barriers to housing for people with I/DD.

- Attended ACRC Supported Living Services Vendor Forum.
- Attended the Board meeting of Housing Now. Housing Now strives to create housing opportunities for persons with I/DD.
- Staff met with RAC Chairperson, Alta Regional Center Resource Development staff person, and 2 housing planners for El Dorado County to discuss county tax incentives and other means the county can use to increase supply of low income, accessible housing or ADUs.
- Staff met with 2 parents and 2 self-advocates to share information about current and future housing options and how to advocate for housing in their IPP process.

4.1 The Council and its federal partners will increase knowledge and awareness for people with I/DD and their families about the availability of and access to health and public safety-related services and supports.

- SACRO co-sponsored the 2018 NICU Family Symposium.
- Staff met with Ben Monroe at the Department of Developmental Services (DDS) to receive Emergency Preparedness folders to distribute at the Supported Life Conference.
- Participated on the Colusa Yuba Sutter ADRC Steering Committee Meeting. The Colusa/Yuba/ Sutter Adult and Disability Resource Connection is a collaborative effort of the Agency on Aging Area 4 and FREED to develop an Aging and Disability Resource Connection (ADRC) in Colusa, Yuba and Sutter Counties.
- Provided an information Table at the Colusa/Yuba/Sutter ADRC Health Fair.

- Presented trainings on Developmental Disabilities to the Sacramento Police Department.
- Staff participated on California Health and Wellness' Disability Advisory Committee.
- Attended and participated in the Yolo County Health Council Meeting.
- Attended the Behavior Services Vendor Forum at Alta California Regional Center for gaining information about services provided to then in turn provide this information to self-advocates, families and providers throughout our 10-county area.
- Staff presented an information table at the UCDavis MIND Institutes Summer Institute.
- Provided a training on Healthy Relationships and Preventing Abuse to self-advocates and staff at The Arc's Studio 700 program in Placer County.
- Participated in a Resource Fair and Inclusive Dance Event at Folsom High School coordinated by an inclusive recreation group called WeEmbrace.

4.2 The Council, its federal partners, and self-advocates will increase information and training to law enforcement, court personnel, health care providers, and/or other care professionals about disability-related health and safety issues.

- Attended the Residential Vendor Forum at ACRC.
 - Staff trained Law Enforcement as part of their as part of their 32 hour Crisis Intervention
 Team (CIT) Training.
 - 25 Police Officers from the Yolo and El Dorado County Police Departments, Cache
 Creek Casino, Corrections Dept. and the Jail.
 - o 55 Police Officers from the Sacramento County Sheriff Department
 - Staff provided an Emergency Preparedness training at the Supported Life Conference.
 - Participated in the Anthem Blue Cross Community Advisory Committee meeting in Grass Valley (Nevada County).
 - Participated in the California Health and Wellness/Health Net Community Advisory Committee.

5.1 The Council and its federal partners will increase knowledge and awareness of developmental milestones and intervention services for families of young

- SACRO staff attended the SANKOPA African-American Parent Support Group coordinated by UCD Mind Institute.
- staff participated as an advisory committee member in the Yolo County Help Me Grow collaboration of resources meeting.
- SACRO sponsored and provided a resource table at the Second Annual Neonatal Intensive Care Units (NICU) Family Symposium in Sacramento.
- 5.2 The Council, in consultation with its federal partners and other stakeholders, will increase awareness and knowledge for families and self-advocates about the availability of and access to services which support inclusive education.

- Attended and provided information and outreach at the Think Transition meetings at the UC Davis MIND Institute in Sacramento.
- Attended and provided information on inclusion (Equality vs Equity; Benefits of Inclusive Classrooms) at the Multi-SELPA Legal Professional Development Series.
- Attended and provided input and written information at the Colusa, El Dorado Nevada,
 Sutter, Yolo, Yuba, San Juan and Sacramento Counties Special Education Local Plan
 Area's (SELPA) Community Advisory Committee (CAC) urging full inclusion in classrooms.
 - Staff created and distributed 8 documents regarding inclusion, education law, and rights for school professionals, teachers and parents titled:
 - 5 benefits of Inclusion Classrooms,
 - Sentence starters to use when talking to teachers,
 - Which laws do what IDEA-ADA-Section 504,
 - Special Education: Federal Law vs. State Law,
 - The difference between ADHD and Autism,
 - Developmental disability Fact Sheet,
 - The Difference between IEP's and 504 Plans,
 - Tips to make sure your Child's IEP is implemented properly, and
 - Parent Rights
- 5.3 The Council, in consultation with its federal partners and in collaboration with educators and stakeholders, will increase information and technical assistance to prepare and empower students, families and professionals in developing individualized transition plans.
 - Attended the Sacramento County Developmental Disabilities Planning and Advisory Council at McClaskey Adult Center, Sacramento.
- 6.2 The Council will increase the knowledge and skills of people with I/DD to move from institutional to community settings and to increase their ability to self-advocate.
 - Attended and shared information with the City of Sacramento Disability Advisory Commission.
 - Participated in a meeting of The ARC Advisory Board meeting.
- 6.3 The Council will increase outreach, training, and technical assistance to improve the quality of and access to services, including (but not limited to) Regional Centers, education, transportation, public benefits, child care, and recreation for people with I/DD and their families.
 - Provided outreach information and participate in the planning of Folsom Parks & Recreation Inclusion project - First Annual RUNWAY 17 Fashion Show.

- Provided an information Table at the Highway Patrol disabilities employment event at the state capital.
- Attended and presented information at the ACRC Board of Directors meeting.
- Attended the Sacramento County Voter Registration and Elections Voting Accessibility Advisory Committee.
- Met with Elizabeth Morabito, Marketing & Publications Consultant with Sacramento News and Review (SN&R) Publications to celebrate the article on inclusion!
- Attended the Placer County Aging Disability and Resource meeting in Placer County.
- Participate in the Planning Meeting for the UC Davis MIND Summer Institute on Neuro-Developmental Disabilities in Sacramento.
- Participate in the Voter's Choice Act Coalition Meeting. 75 community organizations and staff from various state and legislative offices attended. Subcommittees were established and SCDD joined the Field/Outreach Subcommittee.
- Attended the ADRC (Aging and Disability Resource Committee) for Colusa/Sutter/Yuba Counties.
- Attended the Day and Work Program Vendor Forum at Alta California Regional Center.
- Attended the Network Café coordinated by the Sacramento Food Bank and Family Services.
- SCDD Sacramento and Connections for Life staff helped to coordinate a Keynote
 presentation by Chad Carlock from Law Offices of Chad Carlock, LLC. Staff assisted to
 interview and locate 2 self-advocates who could exemplify the legislative changes over
 the past decade including Supported Employment, Supported Living, Employment First
 Policy, and HCBS Settings Rules and full inclusion and access to the community.
- Staff lead a session on Community Inclusion for Individuals with IDD at the 32nd Annual Supported Life Conference in Sacramento.
- Staff provided a training on HCBS Settings Rules called "Inclusion: Changes to the Developmental Disability System in California HCBS" to 16 staff at Easter Seals Day Program in Sacramento.
- Staff and SSAN staff hosted an Information Booth at the ADA Celebration at the California State Capitol.
- Participated in the Community Resource Development Plan at Alta California Regional Center.
- Participated in the Community Development Forum: Building Disability & Financial Partnerships hosted by the CFILC, FDIC, and FHL Bank San Francisco at the Sierra Health Foundation.
- Provided outreach information regarding the Chromosome 22q11.2 Deletion Syndrome Family Meeting at the UC Davis MIND Institute.
- Provided a Voters Choice Act training in collaboration with Disability Rights California and the Secretary of State office staff to 120 self-advocates and 20 family advocates at DDSO day program in Sacramento.

- February 12, 2019 from 10am-1pm at the SCDD Headquarters office (3831 N. Freeway Blvd. Sacramento.
- 10) Topics for next RAC meeting:
 - Holiday potluck ideas?
 - Regional Center Administrator to report
 - Update on legislative priorities
 - o Jordan Lindsay, ARC Executive Director
 - o SCDD/Cindy Smith
 - May need to advocate for federal/state policies related to employment, housing, community integration
 - Members of committees share when meetings they participate in are held/coming up
 - Department of Rehabilitation Overview on services related to our community so that we can understand how they coordinate and share that information.
- 11) Presentation on Help Me Grow in Sacramento and Yolo Counties
 - Nicole Mion Yolo
 - Meghan Murphy Sacramento
- 12) Adjournment Karen Mulvany (FA)

1:30 p.m.



SAC Regional Advisory Committee Minutes Unapproved

| Date | Tuesday, December 11, 2018 |
|----------|---|
| Time | 10:00 a.m 1:00 p.m. |
| Location | 3831 N. Freeway Blvd. Suite 125, Sacramento, CA 95834 |

| Members Present | Members Absent | Others Attending |
|------------------------|-----------------------|-------------------------|
| Karen Mulvany (FA) | Elaine Linn (FA) | Jason Lindo, ACRC |
| Brandy Boyd (FA) | Colleen Moss (FA) | Kenya Martinez |
| Joyce McNair (FA) | Tyler Busselen (SA) | Benita Ayala |
| Christine Hickey (SA) | Glenda Servantes (FA) | Mike - Guest |
| Donnell Kenworthy (FA) | Nancy Esparza (SA) | |
| Jane Taylor (FA) | Tony Biondi (SA) | Ravita Devi, SCDD Staff |
| Tyson Whitman (SA) | Sandra Smith – SCDD | Cindy Smith, SCDD Staff |
| | Representative | |
| Lisa Cooley (SA) | Jesana Tran (FA) | Kathy Brian, SCDD Staff |

| 1) | Call to Order, RAC Member, Brandy Boyd (FA) | | 10:14 a.m. |
|----|--|--------------|------------|
| | a. Welcome RAC Members & Introductions | | |
| 2) | Approval of RAC Agenda, RAC Member, Brandy Boyd (F | A) | (action) |
| | Due to no quorum, no vote was taken. | | |
| 3) | Approval of RAC Minutes from October 23, 2018, Brand | iy Boyd (FA) | (action) |
| | 1 st _no quorum 2 nd | | |

4) Brief reports from RAC members on issues in their counties (2-3 min.)

Karen Mulvany - El Dorado County

Discussed student death after prone restraint in El Dorado County school.

- AB 2657, signed into law 9/30/2018, places new restrictions on the use of seclusion and restraint in schools
- Vulnerability of "Exceptional needs" students
- CalAble.ca.gov→ CalABLE launching on December 18th
- Dale Law Firm → 12/13/2018 online seminar on using ABLE accounts and Special Needs Trusts together at https://vimeo.com/293264581

- Attended the Self- Determination Advisory Committee meeting on November 4, 2018 at Alta Regional Center:
 - 3 year clock for statewide availability of Self Determination began in June 2018.
- Upcoming housing meeting with SCDD staff and El Dorado County
 Planning staff
- The draft Strategic Housing Framework will be sent around soon for public comment (see https://scdd.ca.gov/wp-content/uploads/sites/33/2018/12/STATEWIDE-STRATEGIC-FRAMEWORK-FOR-EXPANDING-HOUSING-OPPORTUNITIES-FOR-PEOPLE-WITH-INTELLECTUAL-AND-DEVELOPMENTAL-DISABILITIES-10.16.pdf)

Donnell Kenworthy - Yolo County

- Death of student (was from Yolo County)
- SELPA CAC → Parent-Information night on January 30th, 2019.

Joyce McNair - Sacramento County

- December 5th Teleconference participated in the group that prepares self-determination program.
- Statewide Group Wavier App. is approved.

Jane Taylor - Nevada County

- Talked about her son and the health benefits for her son needing further assistance.

Brandy Boyd – Sacramento County at Large member

- Reported a delay in Alta Regional services regarding eligibility for her daughter.
- WarmLine Family Resource Center hosted more than hundred people at a Transition fair held at Elementary school in Citrus Heights.

5) Public Comment Period

This item is for members of the public only to provide comments and/or present information to the RAC on matters not on the agenda. Each person will be afforded up to three minutes to speak. Written requests, if any, will be considered first.

-Kenya shared there was a candlelight ceremony at Sacramento Unified School District regarding disparities. You may follow it on social media as well.

- -An El Dorado County student at Guiding Hands School prone restraint incident occurred on November 28th, student was declared deceased on November 30th.
- -Jordan Lindsey with ARC is hosting Capitol Region Disability Organizing Coalition meetings to gather support for future legislation. Looking for parents, vendors, consumers to partner with and move together on the issue
- Public has asked if the Executive Director of The ARC, Jordon Lindsey can speak at our next Regional Advisory Committee meeting.
- Donnell added a man from Kaiser reached out to her about dental care for children through Medi-Cal.
- 6) Statewide Self-Advocacy Network (SSAN) Report, Lisa Cooley (SA)
 - -CalAble to be live and ready to enroll people on December 18, 2018
 - -Thinking Ahead Booklet available at the Department of Developmental Services (DDS)
- 7) Alta California Regional Center (ACRC) Report, Jason Lindo ACRC's Associate Client Services Director

STAFFING UPDATE – ACRC is in the process of growing two new units in order to continue to lower case load ratios. There is a new Case Services Manager in the Grass Valley office, Heidi Dilley. Jessica Markov is now managing a new children and adult unit in the Roseville office. Jessica will be keeping 2 Service Coordinators in the Grass Valley office, as well as managing 10 Service Coordinator positions made up of Service Coordinators who have applied to transfer from other units and new hires. Jessica's unit will give relief to the South Placer area, El Dorado County around El Dorado Hills and Cameron Park and some areas served by the Grass Valley office. This will bring the number of case management units in the Roseville office to 4, one Early Intervention and three units that serve clients 3 and above.

Sacramento Office – Dana Muccular's unit, which was created to give relief to both adult and children's units in the Sacramento office, will become an adult unit. A new children's unit has been created, to be supervised by Angela Mihm, who is currently a Service Coordinator in the Placerville office. These two units will continue to give support to case management units in Sacramento County. This brings the total staff at ACRC up to 502 employees as of 12/11/18.

Self-Determination Program (SDP) Update – Dept. of Developmental Services (DDS) has tentatively set the beginning of February, possibly 2/1/19, for the DDS training

for Regional Center staff for ACRC. We will be one of the training hubs for the state, most likely three other Regional Centers will be joining us. Included in this training by DDS will be the co-chairs of our local Self-Determination Advisory Committee (SDAC), Joyce McNair and Lisa Cooley. After the trainings at all the Regional Centers occur, DDS will be giving Regional Centers 2 to 3 months to onboard staff who will be working with SDP participants; for ACRC this will be the 2 Service Coordinators from each case management unit and their managers as well as our full SDAC. Following this process the mandatory Introductory trainings for SDP participants will occur. Once a client has gone through the training, then planning teams, creation of budgets and hiring of providers can begin for participants.

Training Modules – The training modules DDS will be using have not been released out of draft form, but are anticipated to be released in January, 2019.

Selection of backfill participants – Regional Centers are still waiting for DDS to give us the process they will use to backfill any slots vacated by participants opting out of the initial rollout period. So far, ACRC has had 5 clients indicate they want to withdraw; we also had one of our 179 names drawn that is an inactive case due to lack of contact and we are waiting on word from DDS as to when they will backfill that slot. I have been in touch with the Department several times regarding this particular slot.

FNRC Assistance – I am the liaison for ACRC and FNRC regarding clients relocating either temporarily or transferring from FNRC to Alta due to the Camp Fire. So far we have directly assisted with 19 clients and assisted in the securing of the migrant worker camp facilities in Colusa County being used by approximately 40 clients through April of next year as temporary housing. I expect we will be continuing to absorb FNRC clients for at least the next 3 to 4 months. We have had placements in Care Homes, ICF-DDNs, FFAs and SLS. Our vendors have been very helpful. I am in regular contact, often daily, with FNRC staff and have been since the fire started. Phil Bonnet has been up to FNRC multiple times assisting their Executive Director and staff. One of their large group home providers used to be the agency Phil founded and ran for many years before he entered the Regional Center system.

Medicaid Waiver – ACRC currently has as of October – 12,316 or 58.1% on waiver, second highest in the State. 3rd highest producing in the State in bringing in Medicaid Waiver dollars.

8) Discuss agenda items for next meeting (2/12/19), Brandy Boyd (FA) (action)

- Restraint laws from Disability Rights California on what's allowed and what is not allowed.
- 9) Presentation on current legislation, Cindy Smith SCDD's Deputy Director, Policy and Planning 12:00 p.m.-1:00 p.m.

Cindy Smith discussed the SCDD Policy Priorities for 2019-2020 and provided a written handout of the Policy Priorities:

TIME: 1:14pm

- 1.) Protecting and Enhancing Civil Rights
- 2.) Enhancing Community Living
- 3.) Implementation of Self- Determination Program
- 4.) Guaranteeing Access to Competitive Integrated Employment
- 5.) Ensuring Access to the Community
- 10) Adjournment Brandy Boyd (FA)
 - Next meeting on February 12th



Sacramento Regional Office 3831 N. Freeway Blvd. Ste. 125, Sacramento, CA 95834 916-263-7919

Schedule for 2019

Regional Advisory Committee (RAC) Schedule

| | FEBRUARY | |
|-------------|----------|--------------------------------|
| RAC Meeting | | Tuesday, February 12, 10am-1pm |
| | APRIL | |
| RAC Meeting | | Tuesday, April 16, 10am-1pm |
| | JUNE | |
| RAC Meeting | | Tuesday, June 25, 10am-1pm |
| | AUGUST | |
| RAC Meeting | | Tuesday, August 20, 10am-1pm |
| | OCTOBER | |
| RAC Meeting | | Tuesday, October 15, 10am-1pm |
| | DECEMBER | |
| RAC Meeting | | Tuesday, December 17, 10am-1pm |

^{*}Please call office to double check dates and locations, in case of changes.

NOTE: All are welcome to attend. RAC members should notify SCDD Sac staff, at least 2 days prior to the meeting, if they are unable to attend.



Ensure that Californians with developmental disabilities are guaranteed the same full and equal opportunities for life, liberty, and the pursuit of happiness as all Americans.

January 15, 2019 State Council Meeting Summary

SIGNIFICANT ITEMS

- Swore in two new councilmembers:
 - Julie Neward, a family advocate from San Diego
 - Nicole Adler, a self-advocate from Redwood City
- Presented the Program Performance Report for SCDD's work in 2018
- Presentation by Health and Human Services Agency on Governor Newsom's 2019-2020 Proposed Budget and by the Department of Developmental Services (DDS) on the DDS Budget
- Member Spotlight feat. Jeana Eriksen
- Panel Presentation Projects of Excellence
 - SCDD San Diego Regional Office presented on "Project College"
 - SCDD North Coast Regional Office presented on "In Case of Emergency Cards"
- Film Screening: "Extraordinary People" followed by discussion with Autism Society of America Vice Chair Lori Ireland and Extraordinary Ventures CEO Paige Morrow about employment, HCBS requirements, segregated works sites, and community integration

STATE PLAN INFORMATION

- SCDD work in 2018 reached and impacted:
 - 2,682,914 Californians

EXECUTIVE DIRECTOR REPORT

- Executive Director Aaron Carruthers shared summaries on the following areas:
 - Federal government shutdown impact on SCDD and services used by people with disabilities and families
 - Highlighted opportunities with DDS, the Department of Social Services and CalFresh
 - Updated Council on Conflict of Interest questions from prior meetings
 - Welcomed SCDD Public Information Officer Scott Yates
 - SCDD finished its hiring goals and HQ staff is full

SUMMARY OF COUNCIL ACTIONS

- Council approved the Conflict of Interest Waiver request for the following individual:
 - o GGRC Board Member David De Lira
- Council approved the 2018 Program Performance Report
- Council Chair Sandra Smith appointed Julie Austin as Chair of the LPPC Committee

FUTURE MEETING DATE

 March 12, 2019 – Hilton, Sacramento 10:00 a.m. - 4:00 p.m.



POLICY PRIORITIES 2019-2020

PROTECTING AND ENHANCING CIVIL RIGHTS

Every person with intellectual and developmental disabilities (I/DD) has the right to equality of opportunity, full participation, independent living, and economic self-sufficiency. People with I/DD have the right to be safe at school, work, and in the community. Disparities in access, outcomes, and quality for all services and supports must be addressed. Federal and state programs providing services and supports to people with I/DD must be transparent and accountable. Complexities in the service delivery system must be reduced, and assistance in navigating services and supports should be provided to people with I/DD and their families.

The Council will work to ensure civil rights are protected in federal and state policies. The Council will work to ensure the full and robust implementation and enhancement of recent federal policies that enshrine the values of the ADA including the Workforce Innovation and Opportunities Act (WIOA), Home and Community-Based Services Setting Rule (HCBS), Every Student Succeeds Act (ESSA), and Achieving Better Life Experience (ABLE) Act.

ENHANCING COMMUNITY LIVING

Statewide community-based integrated living options for individuals with I/DD must be increased and enhanced through access to housing programs and subsidies. Community education and integration must be provided. Permanent, affordable, accessible, and sustained housing options must be continually developed to meet both current and future needs. In California, it is estimated that 74 percent of people with I/DD live with family. On average, 138 percent of a person's SSI payment is needed to afford a 1 bedroom apartment.

The Council will work to improve options by implementing the SCDD Housing Framework.

The Council will work to ensure money from closures of the Developmental Centers remains in a dedicated housing fund to support integrated community housing for people with intellectual and developmental disabilities.

IMPLEMENTATION OF SELF-DETERMINATION PROGRAM

Individuals with I/DD and their families must have the option to control their service dollars and their services. The Self-Determination Program (SDP) gives individuals the tools and the basic human right to pursue life, liberty, and happiness in the ways that they choose. The process begins with a Person-Centered Plan which details the individual's unique needs, competencies, and aspirations.

The Council will support, monitor, and evaluate the implementation of the SDP.

GUARANTEEING ACCESS TO COMPETITIVE INTEGRATED EMPLOYMENT

Every person with I/DD must be provided with opportunities for competitive integrated employment (CIE). In California, CIE is the priority outcome for working age individuals with I/DD, regardless of the severity of their disability. Data shows that only 13.6 percent of Californians with I/DD between the ages of 16 – 64 are employed in CIE (compared to the employment rate of the general population in the same age range at 75.7 percent). Policies and practices must promote collaboration between local and state agencies. Policies and practices must remove barriers to CIE through promoting access to information, benefits counseling, job training, inclusive postsecondary education, and ensuring appropriate provider rates that incentivize quality employment outcomes.

The Council will work to ensure full and robust implementation of California's Employment First Law and the implementing of the Blueprint for Change. The Council will work to ensure that policies and practices set expectations for CIE, microenterprise training, and self-employment. The Council will work to incentivize employers and contractors for hiring employees with I/DD.

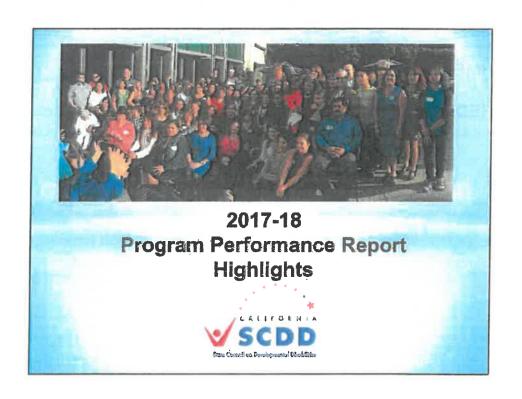
ENSURING ACCESS TO THE COMMUNITY

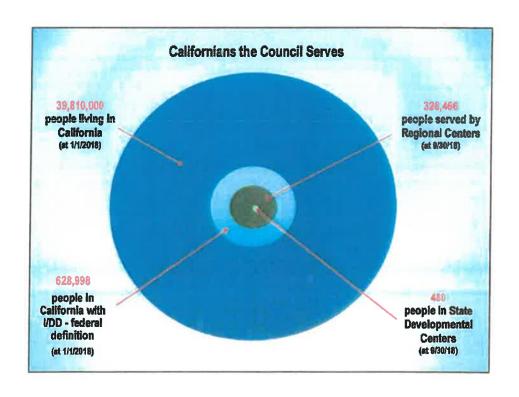
Every person with I/DD must have access to and be fully supported to fully participate in their communities. Community based programs must be funded. Adequate services and supports in the community rely on having adequate wages for providers. The state must increase rates to adequately support the availability of quality services and supports. A planned and systematic approach to rate adjustments must prioritize and incentivize services and supports.

The Council will work to restore the Department of Developmental Services programs that were cut in 2009 including camp and social recreation. The Council will support efforts to provide adequate wages (which is being examined by the Department of Developmental Services' Rate Study). The Council will also work to ensure adequate services and supports by working to ensure effective implementation of the new eligibility for receiving benefits from the CalFresh program.

For more information, contact:

Cindy Smith, Deputy Director for Policy and Public Affairs
Cindy.Smith@scdd.ca.gov
916-263-8113
www.scdd.ca.gov





Goal 1 (Self-Advocacy): Californians with I/DD and their families reflecting the diversity of the state will have increased information and supports to advocate for civil and service rights to achieve self-determination, integration and inclusion in all areas of community life.

Objective 1.1

The Council will increase knowledge about <u>self-determination and</u> <u>person-centered planning</u> by monitoring, supporting and actively engaging in the implementation of the <u>Self-Determination Program</u>.

2017-18 Federal Fiscal Year In Obj. 1.1

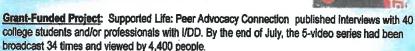
Educated in person through training, events outreach, and informational materials:

- 29 (English) and 12 (Spanish) trainings on Person-Centered Planning to 1,833 people
- 65 (English) and 13 (Spanish) trainings on Self-Determination to 2,063 people
- 3,582 pieces of informational material on PCP distributed
- 7,826 pieces of informational material on Self-Determination
- Supported 2 Statewide SDAC Meetings
- Supported 120 Local SDAC Meetings, reaching 1,604 people

Sample Events:

- Conexiones Educativas Self-Determination Mini-Conference
- Wrightslaw from Emotions to Advocacy Conference with Pat Howey
- Supported Life Conference
- Family Voices Conference
- CHOICES Conference

Electronic Information Distribution: 150 articles to 125,833 people Technical Assistance: 221 occasions impacting 471 people





Goal 1 (Self-Advocacy): Californians with I/DD and their families reflecting the diversity of the state will have increased information and supports to advocate for civil and service rights to achieve self-determination, integration and inclusion in all areas of community life.

Objective 1.2: The Council will promote self-advocates in leadership roles in statewide networks a) through the strengthening of a statewide self-advocacy organization and by supporting selfadvocates; b) within cross-disability leadership coalitions; and c) in training other self-advocates to become leaders.

2017-18 Federal Fiscal Year in Obj. 1.2

Educated in person through events outreach, and informational materials and events:

- SSAN and SAAC convened 3 meetings with more than 300 self-advocates (14 additional meetings were held for 382 self-advocates regarding planning and curriculum development)
- SCDD Supported 140 local self-advocacy groups meetings with more than 1,923 self-advocates throughout California
- SCDD Engaged 36 Partners In Policymaking graduates to share their story with policy makers reaching 301 people

Trainings:

- 14 trainings to 337 self-advocates on training-for-trainers leading to 17 peer-led trainings reaching 431 additional self-advocates
- * Provided 13 trainings on Boardsmanship to more than 3,889 people regarding inclusion of family and self-advocates on policymaking bodies

Support to Self-Advocacy bodies: SSAN: Support to 440 individuals in 45 meetings SSAN outreach to 2,385 self-advocales

SAAC: Support to 192 individuals in 6 meetings SAAC outreach to 67 self-advocates

Electronic Information Distribution:

236 articles to 185,712 people

Technical Assistance: 128 occasions impacting 212 people



Goal 2 (Employment): Californians with I/DD and their families reflecting the diversity of the state will have increased information to obtain competitive, integrated employment.

Objective 2.1: The Council will increase and promote culturally competent strategies and resources that facilitate competitive, integrated employment (CIE) of people with I/DD.

2017-18 Federal Fiscal Year in Obj. 2.1

Educated in person through events outreach, and informational materials:

- 35 events on CIE reaching 5,210 people
- 35 trainings on CIE reaching 1,133 people
- 18 regional cross-disciplinary collaboratives created for 249 individuals and agencies to focus on CIE
- 105 quarterly regional cross-disciplinary collaborative meetings with 1,041 individuals and agencies
- 7 Employment First Committee meetings held
- 28 CIE opportunities for 73 self-advocates were supported through SCDD's 12 regional offices

Sample Events:

- **JobtoberFest**
- Coachella Valley Employment Summit San Diego Workforce Conference
- **Ability Faire**
- College of the Sequola's Comm Resources & Employment Faire

Electronic Information Distribution: 155 articles to 37,652 people Hardcopy Information Distribution: 31 articles to 10.124 people Technical Assistance: 214 occasions to 2,679 people

Grant-Funded Project(s):

- Hope Services Project Search in Monterey County
- EasterSeals Southern California Discovery Fidelity Scale for Customized Employment 1st field-testing in the Nation



UNEMPLOYED

Goal 2 (Employment): Californians with I/DD and their families reflecting the diversity of the state will have increased information to obtain competitive, integrated employment.

Objective 2.2: The Council, in consultation with its federal partners, will increase identification, advocacy and/or sponsorship of legislative, regulatory, <u>policy</u>, procedure and/or practice changes to increase <u>CIE</u> for people with I/DD.

2017-18 Federal Fiscal Year in Obj. 2.2

Educated in person through legislative change and direct contact:

Provided 25 outreach activities to 19,026 people

Meetings

Convened 3 Legislative and Public Policy Committee (LPPC) meetings 12 meetings with policymakers, reaching 132 people 4 EFC meetings

Data and Publications:

1 EFC report distributed to 100 people Updated Data Dashboard on SCDD Website and reached 146 people

Legislative Bills:

4 monitored 2 took a position/sponsored

Technical Assistance:

16 occasions, impacting 24 people



Goal 3 (Housing): Californians with I/DD and their families reflecting the diversity of the state will have increased access to affordable, accessible, safe, and fully integrated housing that provides choice and flexibility regarding where and with whom they live.

Objective 3.1: The Council will work with housing entities to increase the development and/or provision of community housing for people with I/DD.

2017-18 Federal Fiscal Year in Obj. 3.1

Educated in person through events outreach, and informational materials:

4 trainings reaching 113 people/organizations

Sample Events:

- Joint Training with Housing Authorities for Self-Advocates and familles
- Presentation at San Francisco Bay Area Autism Society Annual Conference
- State Steps: Unpacking the Housing Bill Package

Stakeholder Coalitions:

- 33 quarterly stakeholder meetings to increase fully integrated housing reaching 1,013 people
- * Participate in 30 regional DFEH/HUD or Housing Authority meetings with 885 people

Electronic Information Distribution: 28 articles to 20,298 people Technical Assistance: 32 occasions, impacting 102 people

Grant-Funded Project: Lanterman Housing Alliance: Statewide Strategic Framework: Supportive Housing for People with Developmental Disabilities.



Goal 3 (Housing): Californians with I/DD and their families reflecting the diversity of the state will have increased access to affordable, accessible, safe, and fully integrated housing that provides choice and flexibility regarding where and with whom they live.

Objective 3.2: The Council will identify and decrease barriers to housing for people with I/DD.

2017-18 Federal Fiscal Year in Obj. 3.2

Educated in person through trainings, events outreach, and informational materials:

6 trainings on HCBS Final Settings Rule reaching 277 people

5 trainings on Housing in Transition and IPP planning to 84 people

10 trainings on Financial Planning/Public Housing entitlements to 118 people

Sample Events:

- Rural Housing Development Corporation presentation
- Living Options Conference for Farsi-speaking families
- Participated on Community Placement Plan RFPs with local Regional Centers
- Presentations on HCBS Final Settings Rules with local regional center vendors

Electronic Information Distribution: 78 articles to 79,884 people Hardcopy Information Distribution: 40 articles to 9,215 people Technical Assistance: 114 occasions to 471 people



Goal 3: (Housing): Californians with I/DD and their families reflecting the diversity of the state will have increased access to affordable, accessible, safe, and fully integrated housing that provides choice and flexibility regarding where and with whom they live.

Objective 3.3: The Council, in consultation with its federal partners, will increase identification, advocacy and/or sponsorship of legislative, regulatory, policy, procedure and/or practice changes to increase housing for people with I/DD.

2017-18 Federal Fiscal Year in Obj. 3.3

Educated in person through legislative change and direct contact:

14 articles distributed reaching 10,993 people

Testified in Hearings to Policymaking Bodies:

4 times to 199 people

Legislative Bills:

0 monitored

0 took a position/sponsored

Meetings:

18 meetings with policymakers, reaching 318 people

Technical Assistance: 62 occasions impacting 56 people



Goal 4 (Health & Safety): Californians w/ I/DD and their families reflecting the diversity of the state will have increased information to access health, public safety, and related services that meet their needs and health care choices.

Objective 4.1: The Council and its federal partners will increase knowledge and awareness for people with I/DD and their families about the availability of and access to health and public safety-related services and supports.

2017-18 Federal Fiscal Year in Obj. 4.1 Educated in person through training, events outreach, and informational materials: 29 Health/wellness events or community faires reaching 2,908 people 35 trainings about health/access to care issues reaching 1,204 people 24 trainings on Emergency Preparedness/response/recovery reaching 806 people 23 trainings on Personal Safety (incl. Bullying) reaching 2,636 people Sample Events: Mental Health Services Oversight Accountability Commission Various Health and Wellness Community Faires Disability Sports Festival - CSUSB Live Well - San Diego End-of-Life Planning Train-the-trainer Active Shooter & Erner. Preparedness Feeling Safe, Being Safe Electronic Information Distribution: Health-Related Material - 124 articles to 98,458 people Public Safety Related Material - 63 articles to 51,868 people Hardcopy Information Distribution: Health-Related Material - 16 articles to 3,636 people Public Safety Related Material - 42 articles to 9,443 Technical Assistance: 319 provided, impacting 4,128 people

Goal 4 (Health & Safety): Californians w/ I/DD and their families reflecting the diversity of the state will have increased information to access health, public safety, and related services that meet their needs and health care choices.

Objective 4.2: The Council, its federal partners, and self-advocates will increase information and training to law enforcement, court personnel, health care providers, and/or other care professionals about disability-related health and safety issues.

2017-18 Federal Fiscal Year in Obj. 4.2

Educated in person through events outreach, and informational materials:

* 64 trainings reaching 2,243 professionals

Sample Events:

- Crisis Intervention Team (CIT) Training (Multiple)
- LD-37 Training to Academy recults (Multiple)
- LD-37 Training to FTO's (Multiple)
- Training to Licensing Program Analysis (LPAs) with Community Care Licensing (Statewide)
- CalOPTIMA Collaborative
- San Diego's "Take Me Home Program" -

Self-registration for People with Special Needs and Law Enforcement



27 Community Collaboratives met 46 times with 494 participants providing technical assistance on 14 occasions impacting 38 people

Electronic information Distribution: 23 articles to 20,201 people Hardcopy Information Distribution: 10 articles to 3,150 people Technical Assistance: 40 occasions, Impacting 77 people







Goal 4 (Health & Safety): Californians w/ I/DD and their families reflecting the diversity of the state will have increased information to access health, public safety, and related services that meet their needs and health care choices.

Objective 4.3: The Council, in consultation with its federal partners, will increase identification, advocacy and/or sponsorship of legislative, regulatory, policy, procedure and/or practice changes to increase accessibility to health care and public safety services for people with I/DD and their families.

2017-18 Federal Fiscal Year in Obj. 4.3

Meetings:

26 meetings to advocate for health services with 8,571 people 7 collaborative partner meetings on health/public safety to 180 people

Electronic Information Distribution:

26 distributions to 23,077 stakeholders

Technical Assistance:

provided 27 occasions, impacting 110 people

Legislative Bills:

Monitored: 4 Health and 5 Public Safety
Position/Sponsor: -2 Health and 2 Public Safety





Goal 5 (Early Intervention, Education, Transition & Post-Secondary Education): Californians with I/DD and their families reflecting the diversity of the state will have increased information, in order to obtain inclusive education services throughout the lifespan.

Objective 5.1: The Council and its federal partners will increase knowledge and awareness of <u>developmental</u> <u>milestones and intervention</u> services for families of <u>young children</u> and professionals.

2017-18 Federal Fiscal Year in Obj. 5.1

Educated in person through training, events outreach, and informational materials:

Participated in 42 Community Collaborations with 484 people

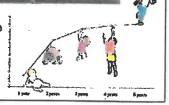
Provided 28 trainings for 361 people about early identification/intervention support/services and/or transition into school

Provided 3 trainings to medical, childcare and/or Early Start professionals reaching 152 people

Sample Events:

- Super Saturday Staff Development Day
- IEP Trainings for School District Staff
- Early Start Symposium(s)
- NICU Symposium(s)
- Child Care Inclusion Symposium(s)
- Native American Networking Collaborative

Electronic Information Distribution: 41 articles to 31,890 people Hardcopy Information Distribution: 24 articles to 3,080 people Technical Assistance: 87 occasions, impacting 1,588 people



Goal 5 (Early Intervention, Education, Transition & Post-Secondary Education): Californians with I/DD and their families reflecting the diversity of the state will have increased information, in order to obtain inclusive education services throughout the lifespan.

Objective 5.2: The Council, in consultation with its federal partners and other stakeholders, will increase awareness and knowledge for families and self-advocates about the availability of and access to services which support inclusive education.

2017-18 Federal Fiscal Year in Obj. 5.2

Educated in person through training, events outreach, and informational materials:

- *83 meetings with collaborative partners and 1,613 people
- 82 trainings on disability awareness/educational self-advocacy reaching 1,802 people
- 21 trainings provided for parent-peer advocacy training (for parent-to-parent) support in the educational system reaching 684 parents

Sample Events:

- * IEP Meetings: How they Work and How to Get What you Need (Parts I & II)
- * T!GER (Training Individuals for Grassroots Education Reform) Training
- * IEP Basics and Advanced Courses

Electronic Information Distribution:

148 articles to 119,947 people

Hardcopy Information Distribution:

66 articles to 22,424 people

Technical Assistance:

482 occasions, impacting 1,737 people



Goal 5 (Early Intervention, Education, Transition & Post-Secondary Education): Californians with I/DD and their families reflecting the diversity of the state will have increased information, in order to obtain inclusive education services throughout the lifespan.

Objective 5.3: The Council, in consultation with its federal partners and in collaboration with educators and stakeholders, will increase information and technical assistance to prepare and empower students, families and professionals in developing individualized transition plans that lead to employment, post-secondary education &/or independent living options & opportunities.

2017-18 Federal Fiscal Year in Obj. 5.3

Educated in person through training, events outreach, and informational materials:

15 trainings to educators and stakeholders reaching 366 people
29 lists of collaborative partners with 330 participants
67 collaborative meetings to develop training resources with 845 partners
8 trainings to self-fiamily-advocates on the student-led IEP/PCP/ITP for 282 people

Post-Secondary Educational Opportunities for Students with a Disability Conference College with A Disability Conference County Transition Faire (Multiple)

Chapman College – Disability Summit Project College Adult Education Task Force (Multiple)

Electronic information Distribution:

68 articles about PCP and ITPs to 55,272 people

Hardcopy Information Distribution:

43 articles about PCP and ITPs to 13,644 people

Technical Assistance: 74 occasions Impacting 139 people



Goal 5 (Early Intervention, Education, Transition & Post-Secondary Education): Californians with I/DD and their families reflecting the diversity of the state will have increased information, in order to obtain inclusive education services throughout the lifespan.

Objective 5.4: The Council, in consultation with its federal partners, will increase identification, advocacy and/or sponsorship of legislative, regulatory, policy, procedure and/or practice changes to increase access to quality education services throughout the lifespan for people with I/DD.

2017-18 Federal Fiscal Year in Obj. 5.4

Testified in Hearings to Policymaking Bodies: 3 times to 76 people

Legislative Bills:

Monitored: 6

Took a Position/Sponsored: 4

16 meetings with policymakers, reaching 346 people

Electronic Information Distribution:

37 articles to 16,505 people

Technical Assistance:

77 occasions, Impacting 110 people



Californians with I/DD and their families reflecting the diversity of the state will have increased information and supports to access community-based services available to the general population.

Objective 6.1: The Council, in collaboration with our federal DD partners, will reduce service access barriers and decrease the disparity In available information, which describes services and supports that may be purchased throughout California's Regional Center system, by translating and providing that Information in Spanish and tracking statewide POS disparity data for Spanish-speaking self-advocates and families.

2017-18 Federal Fiscal Year in Obj. 6.1

Activities:

- 3 Stakeholder meetings with 35 people
- Developed and field-tested 1 list of English lexicon to Spanish translation of I/DD specific terms/phrases with 2 collaborative partners.
- Developed 1 list of Plain Language descriptions of available services through the regional center system in a Q&A format with 3 collaborative partners to field test, develop Spanish translation, curriculum, and training in 2018-2019.

Electronic Information Distribution: 62 articles to 57,955 people

Technical Assistance: 63 occasions, impacting 85 people







Californians with I/DD and their families reflecting the diversity of the state will have increased information and supports to access community-based services available to the general population.

Objective 6.2: The Council will increase the knowledge and skills of people with I/DD to move from institutional to community settings and to increase their ability to self-advocate.

2017-18 Federal Fiscal Year in Obj. 6.2

Educated in person through training, events outreach, and informational materials:

- 13 collaborative meetings to ensure effective crisis intervention and continuity in healthcare with 255 participants
- 21 trainings to Council and RACs on institutional closure process reaching 407 people
- 3 trainings to 64 self-family-advocates on personal/civil rights
- 5 trainings for 324 self-framily-advocates on available supports/services/living options
- 4 trainings for 205 self-family-advocates on PCP/SDP
- 1 training for 13 self-framily-advocates on alternatives to conservatorship
- 4 trainings for 116 self-/family-advocates on personal safety

Sample Events/Trainings:

- You and Your IPP
- Rights of People with Developmental Disabilities
- Alternatives to Conservatorship

Electronic Information Distribution: 8 articles to 6,303 people

Technical Assistance: 18 occasions, impacting 33 people



Californians with I/DD and their families reflecting the diversity of the state will have increased information and supports to access community-based services available to the general population.

Objective 6.3: The Council will increase outreach, training, and technical assistance to improve the quality of and access to services, including (but not limited to) Regional Centers, education, transportation, public benefits, child care, and recreation for people with I/DD and their families.

2017-18 Federal Fiscal Year in Obj. 6.3

Educated in person through training, events outreach, and informational materials:

- 26 Trainings to 449 people on HCBS Settings Rules
- 30 Meetings of Council and RACs serving 550 people
- 13 lists of 337 formal/informal services/support trends, barriers and quality of services
- 28 progress updates provided to 499 parties on HCBS to Council/RACs, stakeholders and other interested parties
- 78 trainings to 2,045 self-family-advocates on Regional Center services
- 53 trainings to 1,142 self-fiamily-advocates on generic services

Sample Events/Trainings:

- Regional Center Disparities: You Can Make a Difference
- Regional Center Services & Fair Hearing Strategies
- Regional Centers, School Districts, and More: How to Give Testimony & Influence Public Policy
- Systems Overview: More than Just Regional Centers
- CalABLE Act
- How Behavior therapy can help (Spanish)
- Disability Annual Dinner and Strategic Planning event

Electronic Information Distribution: 685 articles to 1,301,892 people

Hardcopy Information Distribution: 158 articles to 196,219 people

Technical Assistance: 1,046 occasions impacting 3,121 people

Californians with I/DD and their families reflecting the diversity of the state will have increased information and supports to access community-based services available to the general population

Objective 6.4: Californians with I/DD and their families reflecting the diversity of the state will have increased information and supports to access community-based services available to the general population. The Council, in consultation with its federal partners, will increase Identification, advocacy and/or sponsorship of legislative, regulatory, policy, procedure and/or practice changes to increase access to quality community-based services for people with I/DD and their families.

2017-18 Federal Fiscal Year in Obj. 6.4

Educated in person through legislative change and direct contact:

4 lists of collaborators/stakeholders developed by district distributed to 101 people

Testified in Hearings to Policymaking Bodies:

2 times for 30 people

Legislative Bills:

Monitored: 2 bills

Took a Position/Sponsored: 7 bills

Meetings:

232 meetings with policymakers, reaching 4,000 people

Electronic Information Distribution: 79 articles to 50,111 people

Technical Assistance: 22 occasions, impacting 24 people







STATE OF CALIFORNIA DDS BUDGET SUMMARY

Department of Developmental Services

Governor's Budget Highlights



Gavin Newsom Governor State of California

Michael Wilkening Secretary California Health and Human Services Agency

Nancy Bargmann
Director
Department of Developmental Services

January 2019

The net increase in OPS is primarily due to updated caseload and staffing expenditures.

The increase in POS reflects adjustments for all POS budget categories based on current year expenditure trends.

Specialized Home Monitoring

Increase of \$5.5 million (\$3.7 million GF) to provide required monitoring of specialized homes. One licensed nurse or behavioral specialist will conduct the monitoring for four specialized homes. There will be 93 operational Adult Residential Facilities for Persons with Special Healthcare Needs, 58 operational Enhanced Behavioral Supports Homes and 26 Community Crisis Homes in 2019-20.

Specialized Caseload Ratios

Increase of \$3.8 million (\$2.6 million GF) to establish a 1:25 service coordinator-to-consumer caseload ratio for consumers with complex needs requiring intensive service coordination for stabilization in the least restrictive setting.

Developmental Center Closure/Ongoing Workload

Net increase of \$3.0 million (\$1.5 million GF) to continue regional center workload associated with the ongoing monitoring and coordination of individuals who transition from Developmental Centers. Funding has been shifted from the Agnews and Lanterman Developmental Center Closures to offset the \$8.3 million (\$3.9 million GF) total costs.

Impacts from Other Departments, Behavioral Health Treatment (BHT)
Consumers with no Autism Spectrum Disorder (ASD)

Decrease in savings of \$39.4 million GF due to transition of all Medi-Cal Managed Care consumers with medically necessary BHT services. By the end of 2018-19, all of these consumers will have fully transitioned to Department of Health Care Services (DHCS). As a result, savings from Medi-Cal Managed Care occurred in 2018-19 only. Fee-for-service consumers continue to access services through regional centers and the Department is reimbursed by DHCS. Reimbursements for non-ASD fee-for-service are displayed in Reimbursements from DHCS.

Community Crisis Homes for Children

One-time increase of \$4.5 million GF to develop three community crisis homes for children. The estimated cost to develop each home is \$1.5 million.

Community Placement Plan for DC Closures

Decrease of \$21.6 million (\$14.5 million GF) due to closure of the three remaining Developmental Centers.

Uniform Holiday Schedule

Decrease of \$47.8 million (\$28.7 million GF) due to the expiration of the one-time 2018-19 appropriation that delayed implementation of the Uniform Holiday Schedule. The Department proposes to implement the policy effective July 1, 2019.

SB 3 Minimum Wage, January 1, 2019

Increase of \$76.0 million (\$38.4 million GF) to reflect the estimated full-year cost of the January 1, 2019 California minimum wage increase from \$11.00 to \$12.00 per hour.

SB 3 Minimum Wage, January 1, 2020

Increase of \$83.0 million (\$41.7 million GF) to reflect the estimated half-year cost of the January 1, 2020 California minimum wage increase from \$12.00 to \$13.00 per hour.

Bridge Funding

Decrease of \$42.0 million (\$25.0 million GF) due to the expiration of the one-time appropriation in 2018-19.

STATE OPERATED RESIDENTIAL AND COMMUNITY FACILITIES PROGRAM

<u>2018-19</u>

The DC and STAR Home population was 514 residents on July 1, 2018. The Department projects an ending population of 323 residents on June 30, 2019.

The Governor's Budget updates the 2018-19 Enacted Budget to \$394.4 million (\$306.7 million GF); an increase of \$9.8 million (\$7.5 million GF). The increase is a combination of the following adjustments:

Operations Expenditures

Decrease of \$0.8 million (\$0.3 million GF) in Operations Expense and Equipment (OE&E) costs due to a net reduction of 20 residents compared to 2018-19 Enacted Budget.

Employee Compensation and Retirement

Increase of \$11.6 million increase (\$8.1 million GF) for compensation and retirement adjustments approved through the collective bargaining process and Item 9800 – Employee Compensation Adjustments.

Sonoma and Fairview Lump Sum Leave Balance Payouts

Decrease of \$0.9 million (\$0.3 million GF) as compared to the 2018-19 Enacted Budget to fund lump sum leave balance payouts for separating employees.

2019-20

The Governor's Budget proposes a total of \$309.5 million (\$265.8 million GF) for the State Operated Residential and Community Facilities Program; a decrease of \$84.9 million (\$40.8 million GF) from the 2018-19 updated budget. The decrease reflects the following adjustments:

Operations Expenditures

Decrease of \$82.9 million (\$37.0 million GF) comprised of \$70.5 million in Personal Services and a \$12.4 million in OE&E due to a reduction in resident population. The decrease includes the following adjustments:

• \$11.7 million (\$7.3 million GF) increase and 100.6 positions to operate one

- additional STAR Home in Northern California and to develop two Central Valley STAR homes and a Central Valley Crisis Assessment Stabilization Team (CAST) as part of the Department's ongoing Safety Net planning.
- DC staffing update, decrease of \$105.9 million (\$55.6 million GF), including position reductions from the Sonoma DC closure.
- One-time funding increase of \$5.0 million GF for Deferred Maintenance at Porterville.
- \$1.0 million GF increase for 8.0 Regional Resource Development Project (RRDP) staff required to continue monitoring of Sonoma residents who transitioned to the community.
- \$5.3 million GF increase for the ongoing cost of workers' compensation claims from open and closed facilities.

Employee Compensation and Retirement

Decrease of \$1.4 million (\$0.9 million GF) for employee compensation and retirement adjustments approved through the collective bargaining process. In total, the Governor's Budget includes \$10.1 million (\$7.1 million GF) for employee compensation and retirement adjustments in 2019-20.

<u>Fairview and Porterville General Treatment Area Lump Sum Leave Balance</u> Payouts

Decrease of \$0.6 million (\$2.9 million GF) to fund lump sum leave balance payouts for separating employees. In total the Governor's Budget proposes \$7.7 million (\$4.0 million GF) to fund lump sum leave balance payouts in 2019-20.

CAPITAL OUTLAY

The Governor's Budget does not include a proposal for Capital Outlay funds in 2019-20.

HEADQUARTERS

2018-19

The Governor's Budget updates the 2018-19 Enacted Budget to \$70.9 million (\$42.3 million GF); an increase of \$2.7 million (\$2.2 million GF). The increase is for employee compensation and retirement adjustments approved through the collective bargaining process and Item 9800 – Employee Compensation Adjustments.

2019-20

The Governor's Budget proposes \$84.8 million (\$53.2 million GF) for Headquarters in 2019-20, an increase of \$13.8 million (\$10.9 million GF) compared to the 2018-19 updated budget. The net increase results from the expiration of \$0.4 million GF in one-time funding and an increase for three Budget Change Proposals (BCPs) as detailed below:

Headquarters Restructure and Reorganization

\$8.1 million (\$6.5 million GF) and 54.0 positions to restructure the organization and realign resources to achieve efficient and effective system-wide improvements to better serve Californians in the developmental disabilities services system.

Home and Community-Based Services Assessments

\$3.0 million (\$1.8 million GF) in one-time funds to contract for the coordination and completion of on-site visits and assessments of providers and programs as required by the Home and Community-Based Services final rules.

Federal Claims Reimbursement System Project

\$3.2 million (\$3.0 million GF) for the Federal Reimbursement System Project, a multi-year information technology project to replace the legacy federal billing system that DDS utilizes to claim \$2.8 billion in federal funds annually. This request includes three-year limited term funding for 5.0 positions. The estimated costs for 2020-21 and 2021-22 are outlined in the BCP.

2019 Governor's Budget Program and Funding Summary (Dollars in Thousands)

| | 2018-19* | 2019-20 | Difference |
|---|----------------|----------------|----------------|
| Community Services Program | | | |
| Regional Centers | \$6,892,600 | \$7,398,803 | \$506,203 |
| Totals, Community Services | \$6,892,600 | \$7,398,803 | \$506,203 |
| General Fund | \$4,087,869 | \$4,450,177 | \$362,308 |
| Program Development Fund (PDF) | 2,253 | 2,242 | -11 |
| Developmental Disabilities Svs Acct | 150 | 150 | 0 |
| Federal Trust Fund | 54,276 | 54,276 | Ó |
| Reimbursements | 2,747,312 | 2,891,218 | 143,906 |
| Mental Health Services Fund | 740 | 740 | 0 |
| Developmental Centers Program | | | |
| Personal Services | \$328,468 | \$255,941 | -\$72,527 |
| Operating Expense & Equipment | 65,915 | 53,521 | -12,394 |
| Total, Developmental Centers | \$394,383 | \$309,462 | -\$84,921 |
| General Fund | \$306,682 | \$265,834 | -\$40,848 |
| Federal Trust Fund | 0 | 0 | 0 |
| Lottery Education Fund | 180 | 180 | 0 |
| Reimbursements | 87,521 | 43,448 | -44,073 |
| Headquarters Support | | | |
| Personal Services | 61,754 | 69,442 | 7,688 |
| Operating Expense & Equipment | 9,141 | 15,351_ | 6,210 |
| Total, Headquarters Support | \$70,895 | \$84,793 | \$13,898 |
| General Fund | \$42,314 | \$53,217 | \$10,903 |
| Federal Trust Fund | 2,761 | 2,708 | -53 |
| PDF | 388 | 389 | 1 |
| Reimbursements | 24,953 | 27,999 | 3,046 |
| Mental Health Services Fund | 479 | 480 | 1 |
| Totals, All Programs | \$7,357,878 | \$7,793,058 | \$435,180 |
| Total Funding | | | |
| General Fund | \$4,436,865 | \$4,769,228 | \$332,363 |
| Federal Trust Fund | 57,037 | 56,984 | -53 |
| Lottery Education Fund | 180 | 180 | 0 |
| PDF | 2,641 | 2,631 | -10 |
| Developmental Disabilities Svs Acct | 150 | 150 | 0 |
| Reimbursements | 2,859,786 | 2,962,665 | 102,879 |
| Mental Health Services Fund | 1,219 | 1,220 | 1 |
| Totals, All Funds | \$7,357,878 | \$7,793,058 | \$435,180 |
| Caseloads | E4.4 | 202 | 404 |
| Developmental Centers Regional Centers | 514 333,094 | 323 349,606 | -191 16,512 |
| Departmental Positions | | | • |
| Developmental Centers | 2 102 7 | 2 407 0 | 6040 |
| | 3,182.7 | 2,497.9 | -684.8 |
| Headquarters | 444.0 | 503.0 | 59.0 |

^{*}Total Expenditures do not reflect the statewide item for Employee Retention Incentives of \$20.1 million that was added by the 2016 Budget Act and displayed as a Carryover in the Governor's Budget Galley.



Please read these 3 articles prior to RAC meeting for group discussion (if you need assistance, please contact our office)

- Preventing abuse of your special needs child
- Is California failing its most vulnerable adults
- How a dental clinic is filling a void for those with special needs

Preventing Abuse of Your Special Needs Child (1/15/2019)



Here's a somber statistic: Individuals with intellectual and developmental disabilities are far more likely to be abused by someone they know than a stranger.

Abuse is any behavior that is unwanted, intentionally harmful, demeaning or insulting, or causes the victim to be afraid. This may include physical violence, sexual assault, bullying, emotional maltreatment or neglect.

Sadly, because an individual with intellectual and developmental disability may be perceived as an "easy target," the likelihood of abuse is four to 10 times higher than in typically developing peers. The abuse is more likely to occur repeatedly, over longer periods of time, and is presumed to be underrecognized and underreported.*

Alyssa Siegel, MD, offers parents and guardians tips to keep children with special needs safer from abuse, how to prevent abuse, and what to do if your child does suffer from abuse.

Be familiar with your child's contacts

Get to know all individuals working with your child, including those working in your home, at school, therapy sessions and recreational activities. For caregivers or therapists that you are hiring privately, gather as much information as possible, including educational, employment and criminal history.

If they have previously worked for reputable institutions, it is likely that thorough background checks were done at that time. Investigate references to assure satisfaction in previous employment and departure on good terms. If the position requires professional certification, verify authentic licensure. Be sure that the prospective hire can explain any time gaps on their resume.

For center-based staff, including teachers, make impromptu visits and observe interactions before your child knows you are present.

Educate your child early

Talk to your child about boundaries regarding words and touch. Revisit important concepts as your child's developmental ability and level of understanding changes. Outline the roles of the adults in your child's life and explain how they are expected to speak and behave with your child.

Review forms of discipline, who can impose a punishment, and what types of punishments are acceptable. Review the correct names of body parts. Indicate which body parts are private and when/where touching is OK. Talk about when and where it is OK to remove clothing or show private body parts.

Recently, pictures demonstrating acts of abuse and sexual anatomy have been added to some communication boards used by non-verbal individuals to help them understand and disclose acts of abuse.

Describe sexual abuse in its different forms

This includes inappropriate talk, touch, or showing of pictures, as well as being asked or forced to say, show, or do something that is uncomfortable. Be sure to discuss that unwanted behavior can come from a known individual or a stranger. Talk about how to recognize whether sexual feelings are mutual or one-sided. Explain your child's domain over their own body and their right to say "No" to anything that feels intrusive.

Promote a 'no secrets' policy at home

Create a comfortable and supportive environment for your child to communicate openly. As your child gets older, this should include open discussions about romantic feelings, sexual urges, and relationships. Reinforce that being the victim of unwanted behavior is NOT a secret, even if they have promised not to tell.

Recognize signs of abuse

Evidence of abuse may be either physical or behavioral. Be sure that there is a plausible explanation for any skin markings or bruises, broken bones or head injury. Behavior changes may be subtle and non-specific, but changes in mood, eating habits or sleep, avoidance of school or social situations, or change in response to a specific place or individual may be worrisome.

Abuse may also cause a halt or regression in academic or social progress. Do not accept the suggestion that unusual new behaviors are "part of Down syndrome." If you are concerned, or not quite sure if you should be, speak to your primary care physician for immediate guidance.

Don't underestimate the value of public advocacy

Advocacy organizations, such as The Arc, strive to educate families and the general public about issues important to individuals with Down syndrome and are champions for improved public policy at federal and local levels. The community of parents, medical, legal and educational professionals that dedicate their efforts to exposing and addressing abuse in this population should continue to receive support.

Ever-increasing opportunities for self-advocacy have also empowered teens and young adults with Down syndrome to show the world their strengths and hear their voices. These efforts help to diminish the perceived imbalance of power that abusers exploit as they target individuals with Down syndrome.

* AUTHOR'S NOTE: Information regarding abuse of victims with intellectual and developmental disability is not further subdivided to isolate individuals with Down syndrome. Individuals with Down syndrome are statistically more likely to live with family members than in residential facilities, perhaps conferring a safer environment, hence a lower risk for abuse, than the broader constituency.

Additional resources

- The Arc: Abuse of Children with Intellectual Disability
- Disability Justice: Abuse and Exploitation of People with Developmental Disabilities

Alyssa Siegel, MD, is an attending physician at Children's Hospital of Philadelphia, providing primary care to children and adolescents.

http://www.eparent.com/education/preventing-abuse-of-your-special-needs-child/

Is California Failing Its Most Vulnerable Adults?

Thousands of allegations of abuse and neglect have been made against the programs that care for people with developmental disabilities.

By Justine Calma Published Dec. 11, 2018 (FIVETHIRTYEIGHT, ABC News)

As she waited for her meal during a routine trip to a fast-food restaurant in Northern California's Bay Area in July of last year, a woman with a developmental disability was lured away from her adult day care group. The staffer overseeing the group ordered food, but it wasn't until after he ordered that he realized the woman was missing. C1, as she is identified in state investigation records, was found 30 minutes later in the back seat of a car with a registered sex offender who was later charged with sexual battery, according to the investigation report.

Patricia remembers that day. Her daughter, Jackie, attended the same program. When a staff member dropped off Jackie and told Patricia what had happened, Patricia called in a complaint to the agency that referred her to the day program. A few months later, Patricia made another complaint, this time for her own daughter, fearing that she too had experienced sexual abuse at the day care.

At Patricia's request, FiveThirtyEight agreed not to use her and her daughter's real names, both to protect Jackie's privacy and because Patricia is afraid that coming forward might dissuade other programs from admitting Jackie.

Though they are anonymous, they are not alone.

A joint investigation by The Investigative Fund at The Nation Institute and FiveThirtyEight has found that from 2013 to 2017, there were at least 2,400 reported allegations of abuse and neglect in the more than 4,500 day programs like Jackie's in California.

The goal of adult day care programs is to help clients build their capacities by doing activities in their communities, rather than by being sequestered in live-in institutions. But our findings, along with a series of industry association reports that found funding gaps have affected the quality of care at day programs, suggest that the state's adult day care system has its own problems. This summer, 51-year-old Timothy Cortinas was found dead in a car in West Covina, California; a lawsuit alleges that he was left alone in the vehicle for hours by a day care staff member as temperatures inside the car climbed to over 100 degrees.

C1 and Jackie, who has Down syndrome, are among the people most vulnerable to sexual, physical and emotional abuse. People with intellectual disabilities are <u>seven times more likely to experience sexual assault</u> than people without any disabilities, according to the U.S. Justice

Department. A <u>nationwide movement</u> has increasingly held people in authority accountable for sexual abuse. But people with developmental disabilities — particularly those whose disabilities affect communication — encounter many additional hurdles before their cries of "me too" are heard.

Adult day programs like Jackie's are part of California's decades-long search for alternatives to institutionalization, which segregated and isolated people, according to advocates. Many people with intellectual and developmental disabilities have historically lived in institutions that provide 24-hour care, some of which have come under scrutiny for keeping abuse behind closed doors. The state's 1969 Lanterman Act entitled people with developmental disabilities to services that would help them live the most independent lives possible, and it put California at the forefront of a national push to give people the support to live at home while working or attending programming during the day.

As part of the Lanterman Act, California established 21 nonprofit regional centers connecting individuals with state-vetted services, including day programs. From 2008 to 2016, the number of people attending day programs grew from roughly 51,000 to nearly 70,000 people, according to the State Council on Developmental Disabilities. Clients must receive services through the regional centers to qualify for state and federal funding that will cover the cost of attending a day program.

Some of those clients and their family members have reported dangerous conditions. Hundreds of allegations of abuse and neglect at adult day programs are reported to the state each year.

There are a couple of ways that the state can be notified about an incident. One is by the day programs themselves. When there is suspected abuse or neglect at an adult day program, the program is required to submit a report to the regional center that verified the program meets state requirements and standards. The regional centers, in turn, pass along the reports to the California Department of Developmental Services, which contracts with the regional centers.

According to records that we obtained through a California Public Records Act request to the department, adult day programs in California self-reported 1,964 incidents of suspected abuse from January 2013 to December 2017. Those incidents include sexual, emotional, mental and physical abuse, among other allegations. In the same period, there were 463 allegations of neglect.

When shown the findings, Leslie Morrison, director of external relations at Disability Rights California, a leading advocacy organization, said: "It is shocking. That is a high number. We would like to see a number closer to zero." She added that abuse and neglect are typically underreported.

It's unclear how many of those allegations resulted in citations or other penalties against adult day programs. The department told FiveThirtyEight that information about outcomes wasn't available.

The Department of Developmental Services declined to provide a representative to be interviewed for this article; in a brief statement, however, it said that all reports of what the state calls "special" incidents "are reviewed on a daily basis by staff to determine if the correct entities were notified, if the appropriate actions were taken to ensure the health and safety of impacted individuals, and that safeguards are implemented to avoid a recurrence."

The "special incident report" data set covers all of the roughly 4,500 adult day care programs in the state. However, there is an important distinction between types of programs: While all day programs are "vendors" authorized by regional centers, some are licensed, and others are not. Licensed programs are those based out of a central facility, while non-licensed ones are "programs without walls," in which staff members work with clients in locations throughout the community, such as parks or shopping malls.

Another state agency, the Department of Social Services, also receives special incident reports, but only those from the day programs that it licenses. Members of the public — including clients' relatives, bystanders or day care program employees — can also notify Social Services about allegations of abuse or neglect at a licensed program through a separate "complaint" process. And the public can access information about the history of allegations and citations that have been leveled against each licensed program through an online search tool that is updated by the department.

But more than 2,000 of California's programs are not licensed.¹

Although these day programs must apply to be a vendor with the regional centers, they are not inspected on an annual basis.

For these programs, clients and their relatives are unable to search a public registry to find out whether there have been problems in the past.

Unlike with the "special incident reports," we do have some sense of how often authorities substantiate allegations made to the Department of Social Services through the second mechanism, the complaint process. According to data we received in response to a public records request to the department, there were 783 complaints made in the more than 1,000 programs that Social Services tracks between December 2012 and December 2017. The complaints encompass any allegations of a licensing regulation or law being violated. Of those complaints, 377 led to at least one substantiated allegation by Social Services, and 211 led to at least one Type A citation, which is given for violations that posed an immediate threat to a client's health and safety.²

It's not clear how much overlap there is between the Department of Developmental Services' data set and the data we received from the Department of Social Services.

Jackie's mother made one of those 783 complaints.

Patricia moved to a new city in the San Francisco Bay Area in 2014 with Jackie, who was then in her late 20s. Once there, Patricia relied on the local regional center to find a safe place for Jackie to spend her days and meet new people in the area. She said she didn't expect that finding a

program she and her daughter were happy with would be so difficult or that finding recourse for the abuse she says Jackie experienced would be so challenging.

Their story points to how difficult it is for nonverbal clients to provide evidence of an alleged assault and how hard it is for authorities to investigate the allegations.

The Regional Center of the East Bay referred Jackie to several day programs, and Patricia chose Mission Hope, which has four locations in Northern California. "They said, 'This place is good; we recommend you put her in Mission Hope.' When they recommended it, I trusted that," Patricia said.

But instead of seeing her daughter learn and grow in the program, Patricia said, she saw Jackie regress. Jackie started having screaming episodes when she was upset, something her mother says she didn't do before.

Patricia pulled Jackie out of Mission Hope and called in a complaint to the regional center to report that she suspected her daughter had been sexually abused by a male staff member.

Jackie didn't seem like herself, Patricia said. At night, Jackie, who speaks only a word or two at a time because of her disabilities, repeatedly said, "bad" and "time out," according to her mother. Then, right before Thanksgiving last year, Jackie did something that Patricia said was new — a behavior that was a red flag for Patricia. Jackie pulled down her shirt and showed her chest to relatives.

Because of the severity of her disabilities, Jackie is in many ways like a child. As a result, Patricia said, she had taken care not to expose Jackie to sexual activity on TV or anywhere else. Patricia tried talking to Jackie to find out where she'd learned that behavior. Patricia said that when she asked Jackie why she had pulled her shirt down, Jackie said the word, "man."

Mission Hope's day programs are licensed by the Department of Social Services, which launched an investigation. And because the case involved an allegation of sexual assault, local police were alerted and also opened an investigation. Each of these entities sent someone to interview Patricia. They also interviewed staff members at Mission Hope, who, according to the police report, said they never saw a male staff member interacting inappropriately with Jackie.

Getting Jackie's testimony, however, proved to be more difficult.

At a young age, Patricia started using a technique with Jackie called "facilitated communication" that has been generally <u>discredited</u> by the scientific community. It's supposed to be a way to communicate with those who otherwise can't speak. But it relies upon a third party to guide someone's hand or elbow as the individual points to letters or symbols on a device like an iPad.

After Jackie exposed her chest to relatives but before Patricia filed her complaint, Patricia used this technique with Jackie. Patricia said that she and her daughter typed several messages, which were included in the police report: "he touched me on top and said don't talk to mom about it... he touched my bottom... he touched me for him to feel good... too sad."

James Todd is a professor of psychology at Eastern Michigan University and has served as an expert witness on cases involving facilitated communication, including the <u>Anna Stubblefield case</u>, in which a woman accused of sexually assaulting a nonverbal adult defended herself by pointing to facilitated communication messages in which he consented to sexual contact. When asked what the scientific consensus is on facilitated communication, Todd pointed to decades of scientific study and said, "The only consistent finding is that the facilitator is the author."

The police report did not note that the messages had been typed using facilitated communication, which is also known as supported typing. Patricia believed the messages meant that Jackie was being abused, and she said she had other evidence. A bruise had appeared on Jackie's backside a few days before she exposed her chest to family members, Patricia said, and Jackie had started having nightmares and screaming out at night.

Mission Hope administrator Nissie Escolano and California's Department of Social Services said they could not comment on any specific person's case, including Jackie's or C1's. Escolano did offer this general comment: "Any complaint we take seriously and we always do a full investigation. We call the proper authorities because we are mandated reporters."

The investigations by police and Social Services hit a wall. Patricia said the Fremont Police Department wanted Jackie to be interviewed without her, but Patricia insisted on being present. Without Patricia's consenting to Jackie's being interviewed, law enforcement suspended the case, according to the police report dated Nov. 22, 2017. The report said the police department asked Patricia whether she wanted to proceed with the investigation and that she responded that she did not want to "further traumatize" her daughter.

Morrison, the disability-rights advocate, said that it's not always recommended to have a family member present during an interview. For example, a client might be afraid to discuss consensual sexual activity if he or she is worried that a parent will disapprove. But, Morrison said, an advocate for the client should be in the room.

Lt. Michael Tegner of the Fremont Police Department would not comment specifically on the case but described the department's protocol for working with a minor or a victim with a developmental disability when they are investigating a sexual assault allegation. "The most important part is obviously to try to get information from the victim themselves," Tegner said. To do this, the department works with the Child Abuse Listening Interviewing and Coordination Center in Alameda County, which aims to provide a comfortable space for minors or other victims of abuse to tell a child interview specialist one-on-one what happened.

In February, after interviewing staff members at Mission Hope, the Department of Social Services decided that the allegation of sexual assault was "unsubstantiated." Citing Patricia's refusal to move forward with the interview at the Alameda County center, the investigation report said that "due to lack of cooperation from victim and/or responsible party, the investigation has stalled."

In an interview, Michael Weston, deputy director of public affairs for the Department of Social Services, said the department makes every effort to communicate with nonverbal clients.

"Obviously if you have a client ... who is nonverbal who cannot communicate, that would hinder the investigation," he said. "But there are other ways to go about gathering that information."

Patricia bristles at the claim that her "lack of cooperation" was a major reason that the complaint was dismissed. "The system should be fitting into our lives and serve our handicapped people: 'Let's see how we can help them," Patricia said. "The heartbreak is too much for me."

Advocates for people with disabilities say it's a problem when there aren't adequate attempts to communicate with the person who may have been abused or neglected. "We see all kinds of bias that goes on in some of these investigations where they don't interview the victim ... don't interview other people who are living in the same unit or in the same day program," Morrison said. "Certainly victims who are nonverbal could have other means of expression. And I think that law enforcement and other investigators didn't always take the time necessary to accommodate the disability."

These considerations go beyond Jackie. In another case involving Mission Hope, a bystander at a park called the day program to report that she saw a staff person slap a client in the face, elbow the client at the neck and slap the client's mouth with a plastic spoon on Sept. 19, 2017. The Department of Social Services interviewed the staff member in question but wrote in its report that an interview with the client "was not conducted due to [subject] is nonverbal." The department's investigation did not result in a citation for abuse or any deficiencies, although Mission Hope did separate the staff person from the client. Had the investigation concluded that there was a violation of the client's personal rights — which include, among other protections, that clients are "free from corporal or unusual punishment, infliction of pain, [and] humiliation" — it would have issued the program a citation. (It is unclear whether the staff person still works at the facility. Mission Hope declined to comment on this case.)

In a review of dozens of investigation reports accessed via the Social Services Department online search tool, we identified multiple cases, like Jackie's, in which allegations of abuse or neglect against nonverbal clients weren't substantiated and the clients had not been interviewed. Weston said that documentation in a report that the Social Services Department was unable to interview a client "is not an indicator that other means of interviewing were not explored."

Thousands of allegations of abuse and neglect are not the only signs of California's fraying system of care for adults with developmental disabilities. Since California passed the Lanterman Act 50 years ago, decades of funding challenges have led to a system that employees and regional centers themselves have said is overstretched.

According to California's Department of Developmental Services, adult day programs for people with developmental disabilities cost taxpayers \$1.1 billion in the 2017-18 fiscal year. Still, program funding for developmentally disabled adults in California has stagnated. The rates at which day programs are reimbursed by the state aren't much higher today than they were in 2000, costing, depending on the service, between \$50 and \$89 per person per day in 2017, compared with about \$45 to \$80 in 2000.

In a 2014 <u>report</u>, the Association of Regional Center Agencies said the quality of services provided "is directly related to staff qualifications, retention and continuity of care." But the goal of providing quality care, according to the report, "is unachievable within the limitations of the current rates."

The state is also conducting a study to assess the current reimbursement rates for day programs and address the "sustainability, quality, and transparency of community-based services," according to a statement from the Department of Developmental Services to FiveThirtyEight. If rates had kept up with inflation in the state, the regional center association estimates that by now they should have reached about \$62 to \$115 per person per day.

In a 2015 report, the association described California's developmental services system as being "on the brink of collapse." Amy Westling, the organization's director, said "the state encountered one fiscal crisis after another," leaving the system hamstrung. Regional centers are themselves stretched thin. The state mandates an average caseload for service coordinators, who refer clients and their families to day programs, of 1 coordinator to 62 clients. But, according to Westling, the coordinators have been handling far more.

In 2016, the California state budget provided an increase of \$17 million in ongoing funds to support additional regional center service coordinator positions. But, Westling said, the caseloads the regional centers are dealing with continue to grow at a rapid pace — 15,000 new clients are expected to enter the developmental services system this fiscal year.

Given the underfunding, many day programs are under pressure to attract and retain qualified employees. Staffers in some programs earn California's minimum wage, \$11 an hour. "Their work is much more than that level," said Nancy Eddy, who runs a nonprofit day program tailored for people who are deaf. "They can go to McDonald's and work for that." She said she still struggles to keep her employees, whom she pays \$14 an hour.

Lisa Kleinbub, the director at the Regional Center of the East Bay, said, "People working in direct care services should not be receiving minimum wage. It requires more than that, and it is a profession." Instead of retaining staff long enough to develop expertise and rapport with clients, day programs are losing employees to better-paying jobs.

Staffers are also not required to undergo much training before starting their jobs despite shouldering huge responsibilities with little supervision. They are required to have only eight hours of training when they start, and each year, they need to renew those eight hours. Otherwise, they have no other legally mandated requirements. In contrast, special education teachers in California schools must have a degree and credentials to work with the same population. But after someone with a developmental disability finishes school and enters an adult day program, those personnel requirements disappear.

Katie Hornberger, director of the Office of Clients' Rights Advocacy at Disability Rights California, said she is appalled at the low level of training that employees charged with caring for clients receive. "These are our most vulnerable folks, but yet all of the caregivers we put around them are low-wage workers with the least training, the least education," she said. "As a

society, what have we decided is important? Unfortunately we have decided that people with disabilities are not that important, and we have relegated them to lower levels of care and support."

When working with adults with developmental disabilities, the stakes are often high, and tragedy can come quickly. Patrick Melia filed a lawsuit against Cole Vocational Services after his son, who was nonverbal, died while in the care of one of Cole's day programs in 2012. While the person in charge of taking care of Michael made an unauthorized stop at home to check on the staffer's infant son, Michael was left alone in the car with his food — even though he required 24-hour supervision and was known to choke while eating. The staff member returned to his car to find Michael had choked on his lunch and died.

Shortly after, according to police reports, Michael Melia's caretaker attempted to kill himself by drinking laundry detergent. He told police that after Michael's death, he would have no steady source of income and that he had hoped his life insurance would provide for his family.

Cole Vocational Services, which is part of the Mentor Network, a large provider that operates in 16 states, declined to comment on the case.

Conditions at the day programs have also posed problems for staffers, some of whom say they have faced labor abuses and injury in the workplace. In 2015, workers filed a class-action lawsuit against Mission Hope, which they allege failed to provide meal breaks. Mission Hope did not respond to repeated requests to comment on the lawsuit, which is not yet resolved.

Cole Vocational Services also settled a class-action lawsuit in 2017 that was brought by employees; the suit accused Cole of meal and rest period violations and failure to pay minimum wage and overtime.

"Our settlement should not be viewed as an admission that we violated any laws, as that was never determined in the case," a representative of Cole Vocational Services said in a statement. "As an organization, we strive to comply with all aspects of the law and compliance with wage and hour laws is no exception."

Those who work in day programs say that even with these class-action lawsuits, little is changing. A person who has worked as a direct care staff member in day programs for over 20 years said he tore a muscle in his arm last year when a client fell on top of him at work. FiveThirtyEight granted him anonymity because he feared repercussion from his employer. He's now in his 70s and earns \$11 an hour. This year, his day program began instructing direct care staff members to make sure to take a paid lunch break — but they must still eat with their wards. "We can't leave our clients anyway," he said. "It's still the same. ... They overwork us, making us take care of more clients than we can handle at a time."

Since Jackie left Mission Hope, Patricia hasn't been able to find another program that has an opening for Jackie to join. For the past year, Jackie has stayed at home with her mother. An aide provided by the state stops by the house for several hours a few days a week, but Patricia worries

that Jackie has little to do but watch her cherished collection of children's movies and rifle through her mom's purse to organize the items inside.

There is already a shortage of service providers in California, which means that parents and clients have fewer choices when trying to find a program that will best serve them.

When she gets frustrated, Jackie sometimes bangs her head on the kitchen table. "I'm sorry you're so upset. I wish that you could calm yourself. I know you hurt your head," Patricia speaks to her softly, almost in a whisper. "I'm sorry."

This article was reported in partnership with <u>The Investigative Fund at The Nation Institute</u>.

Maggie Koerth-Baker contributed reporting.

Footnotes

- 1. Although these day programs must apply to be a vendor with the regional centers, they are not inspected on an annual basis.
- 2. It's not clear how much overlap there is between the Department of Developmental Services' data set and the data we received from the Department of Social Services.

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How A Dental Clinic Is Filling A Void For Those With Special Needs

by Cindy Dampier, Chicago Tribune/TNS | January 16, 2019



Andy Mirchell awakers after he received 23 fillings and eight teeth were extracted following oral surgery at St. Bernard Hospital's deptal clinic (Antonio Perez/Chicago, Tribune/TNS)

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CHICAGO — In a sunlit room down a white hallway in St. Bernard Hospital on Chicago's South Side, Francine and Rodney Mitchell are waiting.

Their teenage son, Andy, lies on an operating table not far away, asleep amid the beeps of monitors, the hiss and thump of an oxygen machine, and the unmistakable, high-pitched whir of a dental drill. Andy has intellectual and physical disabilities, is not easily able to communicate or control his own body, and though he has survived and even thrived under the care of two dedicated parents, routine dental care has been difficult to obtain.

Like many people with special needs in the U.S., Andy has suffered with untreated tooth decay. He has been in pain and now has cavities in 23 teeth, bone loss around his front teeth, and eight teeth that will need to be extracted before his treatment today is over. "He can't really tell you when something hurts," says his father. "He'll just ball up and cry."

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The Mitchells knew that Andy's teeth needed care but struggled to find dentists who were willing or able to help. "We tried to take him to a neighborhood clinic," Rodney says, "but they didn't want to touch him. A lot of dentists won't touch special-needs people." Rodney also took Andy, in his wheelchair, to an open clinic day at the University of Illinois at Chicago, one of the few places that is known as a treatment option for patients with special needs. They left home at 6 a.m., but when they arrived, he says, the line was like Disney World — hourslong. They gave up and went back home.

Finally, through staff at La Rabida Children's Hospital, the Mitchells heard about a dental clinic at St. Bernard.

'There is nowhere else for them to go'

Monique Davis, the office manager for the dental clinic, steps into the room, and the Mitchells eye her somewhat warily. Davis beams — it's just what she does. She spends her days bustling through the hospital hallways, keeping the clinic on track, but her main job, as she sees it, is to reassure and make comfortable people whose everyday struggle has honed their tenacity to a sharp edge. Her mission is clear: She is here to help. "We specialize in special-

needs patients," she tells the Mitchells. "There is nowhere else for them to go, so even if insurance becomes a problem, we will work with you. We are just a small community hospital, but we see everybody here. We do everything." The Mitchells are quiet, but they nod, ask a couple of questions, relax a bit. Davis smiles her huge smile again. "Don't worry," she says. "We're taking care of him now."

By many measures, the hospital dental clinic at St. Bernard seems an unlikely place of refuge. Situated near the Dan Ryan Expressway in Englewood, a neighborhood which has long been used as Chicago shorthand for urban blight and crime, it's in a squatty, unassuming brick hospital building on a quiet street. Police cars come and go outside the emergency room entrance, and a steady stream of visitors and patients make their way past the security desk at the main door. The hospital lacks a marquee reputation among the city's lauded medical centers. There is no groundbreaking medical research here.

Instead, there is an unlikely group of people who have found an unusual sense of purpose around fixing teeth. "When I became a dentist," says Dr. Mary Joyce Gomez, director of the St. Bernard dental clinic, "I wanted to be a pastor, a minister. My mom said, 'No, you be a doctor, you can serve people that way.' I was thinking, 'How can you really serve people by just filling their teeth?" A year and a half ago, Gomez gave up a comfortable private practice in the Loop to become dental director at St. Bernard because, she says, she realized she had found a place where she could finally realize that dream.

'The haves and have-nots'

The St. Bernard dental clinic, founded in 2007, treats a patient population that is largely insured by Medicaid. Under Gomez's leadership, the clinic expanded its mission. Though services were available for children with special needs, she added care for adults with special needs — a group that finds dental care extremely hard to access.

"Oral care in the U.S. is really a story of the haves and have-nots," says Jane Koppelman, senior manager of the Pew Charitable Trust's dental campaign. "It is not a problem for the well-off, but it's an incredible problem for people who are low-income." Since 2008, Pew has been studying dental health in America, and its research has revealed that about 30 percent of the U.S. population has no access to dental care. That number is disproportionately made up of low-income Americans. "Dental care," says Koppelman, "is out of reach for 125 million Americans." Cost is the principal barrier, but access plays a role too: "There are large pockets of underserved areas in inner cities, rural areas or other areas where dentists and other health care practitioners don't care to reside or practice," says Koppelman.

Though there is little data on patients with special needs, specifically, "anecdotally," says Koppelman, "we have seen that the issue for special-needs populations is particularly acute." Patients with special needs are often unable to sit in a dental chair for routine care or longer procedures, and thus are more apt to need general anesthesia, which few dental offices can provide. In addition, this population may have a greater barrier to transportation and other basic concerns involved in getting to a dentist. Among the subset of dentists who treat patients with special needs, many treat only children, meaning that even those patients who can get care may age out of access to that service.

For patients or caregivers who have already navigated so many hurdles, finding a welcome like the one at St. Bernard can seem nearly miraculous. In a world that often answers "no," the dental clinic is a place built on "yes."

"I teach my staff," Gomez says, "we don't turn anyone away."

Living on hope

She understands adversity, she says, because she has had to navigate a few hurdles of her own to get to this place. Growing up in the Philippines, she was the daughter of a dentist father and a mother who doggedly pursued her own

education after being orphaned. "She was the one with the vision," Gomez says, and her vision for her children was that they would all be doctors. Her father, she recalls, "would always tease me and say, 'Your feet are like mine. Maybe you will follow in my shoes." When he died, just before she turned 18, her mother only pushed harder to ensure her children's success. In time, Gomez's brother became a physicist with a doctorate, her sister a medical doctor, and Gomez a dentist.

"I was fine practicing in the Philippines," she says, but on a visit to the U.S. to see her brother in Maryland, her mother decided that America was the place for Gomez, as well. "She said, you will be successful here." Somewhat reluctantly, Gomez agreed to try, and traveled to California to take a bench test that would allow her to receive a U.S. license to practice. Her mother, who had planned to come along to support her, had been diagnosed with cancer and had to remain behind. "The test was on Friday," she says. "On Wednesday night, she called me and prayed for me. On Thursday night, she died."

Determined to go on because it was what her mother wanted, Gomez took the test the next day and passed — only to learn that the program that would have allowed her to receive a license after passing the test had been discontinued.

She applied for a green card, intending to go to dental school in the U.S. "That was in 2000," she says. "And in 2001, 9/11 happened. So the green card that would have taken three years took nine." She waited, working as a dental assistant in Maryland for nine years. "By the time I finally got the green card," she says, "I told my husband, 'I'm too old for this now!'" Still, she applied and was accepted at the University of Illinois at Chicago College of Dentistry.

A year into the program, she faced another setback: "I felt a lump and was diagnosed with breast cancer."

At school, she was initially told she would need to reapply to the dental program once her treatment was finished. "I felt like everything crashed in on me," she says. "I was living on the hope that there was a plan of me becoming

a dentist, but now I'm sick, I am in dental school. Now I have student loans. How am I going to pay this? How am I going to pay rent?" In the end, a sympathetic dean relented and helped her return to the program once she was well, and she graduated in the top of her class.

After graduation, she took a residency in Peoria, working with low-income populations. "Many of them were feeling, 'How am I going to lift myself up out of this? I have no money. I have nothing.' And we were like a beacon of hope. We gave them a little bit of hope. And all of a sudden, you would see them transformed."

She saw firsthand the impact dental health has on many aspects of life: Poor dental care is not only the source of chronic pain that results in poor performance and absenteeism at work and in school, but can be the source of deteriorating health overall. Today, according to the American Dental Association and the Surgeon General, studies suggest links between oral health and diabetes, heart disease and stroke, and lack of proper dental care has been viewed as part of an ongoing public health crisis for more than a decade.

But Gomez was also interested in the psychosocial effects of better dental care. According to the American Dental Association, 37 percent of low-income adults in Illinois say that the condition of their mouth or teeth affects their ability to interview for a job. "We would give them a total smile makeover," she says, "and all of a sudden, they would come in smiling, looking up. 'Hey, I went for a job interview.'" For Gomez, the effects were revelatory: "I saw a patient population that I could touch."

'This might be it'

Though she settled into a comfortable routine with a private practice in downtown Chicago, Gomez felt that something was missing. Then, in 2017, she saw a job posting for a new dental director at St. Bernard. In her mind, something clicked into place. "Sometimes people think of dentistry as just

filling teeth," she says, "or you do it for the money. But there is something there that you need to find, something to move you. I saw this job, and I thought, 'This might be it.'"

Suddenly, she saw her own path in life in a new light. "All those experiences, see how they fall into place? Being on the side of being the patient made me more compassionate to the patients. Being an assistant for a long time made me understand the staff. I understand them when they are tired, frustrated — been there, done that. All the obstacles and hindrances make me more thankful, more grateful every day. So now everything has a meaning. We have to care."

The more she researched St. Bernard, the neighborhood, the work to be done, the more strongly she felt about her mission. Colleagues questioned the idea, "'Are you sure you want to go there?' And even my husband and my brother weren't sure. But they know me, I am …" she laughs, "kind of stubborn, you know, in a nice way. I'm like, 'OK, yes, I will consider that. Thank you for your input.' But my mind is made up."

Knowing she would need to put all of her energy into the work at St. Bernard, she sold her downtown practice. "This is a full-time-plus-100 job," she says. "I put everything here — not only my time, but everything, I'm so invested."

Once at St. Bernard, she began recruiting other dentists, exploring partnerships with UIC dentists and dealing with a patient backlog. She sought out like-minded young dentists like Abby Stern and Chi-Lan Pham, who are starting in public service dentistry fresh from dental school.

"You feel this weight of being the only one who will see these patients," says Stern, "of wanting to do your job well enough that you are able to be that for them." Stern isn't sure everyone understands that urgency. "My parents are still surprised that this is the route I took," she says. "I think they still think I'm going into private practice. It's just the perception, 'Oh you're going to go to dental school, you're going to make a lot of money, you're going to have a

comfortable life." But, like Gomez, that isn't what Stern has in mind: "I want to be in public health for my career. I want to pursue it not for any income or status but just to better the community. There's a lot of need, and we see it every day."

Gomez is intent on meeting that need, whether it means wearing a crown to turn a kid's dental visit into a visit from a tooth-fairy princess, or spending her day in the operating room, performing multiple extractions and fillings on a 47-year-old patient with special needs whose anxiety wouldn't allow her to sit still for dental X-rays.

The issue of better dental care for low-income people and patients with special needs is a nearly overwhelming problem, but her goals go beyond meeting that need. In a community that has rarely been afforded even the basic services that are readily available elsewhere in Chicago, Gomez believes that she can make a difference that starts with fixing teeth, and goes much further.

"Every day, I see so much anger in people," she says. "When you're angry, you get anger back. But I try to impress on our staff that people come here with all kinds of other problems. Don't take it personally like they are mad at you, but treat them with care. Because when you treat them with care, they will feel it, and when they feel it, that changes the whole thing. They will understand that there are still people out there who care."

Her mission — her ministry — has always been about more than fillings and root canals. "It's not only the teeth, it's the people that we can care for. We need to care for them, give them what they need and also a little bit of hope."

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